

# MAKING A DIFFERENCE? UNDERSTANDING THE WORKING LIVES OF LEARNING DISABILITY NURSES: 30 YEARS OF LEARNING DISABILITY NURSING IN ENGLAND

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## ***Abstract***

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The study aimed to explore the lived experience of the careers of learning disability nurses in England. The methodology was informed by Hermeneutic Phenomenology, and the study design utilised narrative interviewing techniques based on an adapted model of the Biographic Narrative Interpretive Method (Wengraf 2001) in order to explore the career choices, experiences and beliefs, and values about learning disability nursing. Twenty in-depth qualitative interviews with learning disability nurses, who had been in practice in the 30-year period between 1979 and 2009, were undertaken in 2010 across nine counties in England. The data was interpreted using a narrative analysis approach. Key findings indicated that nurses, working in a diverse range of settings with varying degrees of experience, are motivated by working with people with learning disabilities and narrate their experiences of building relationships with people articulating the meaning of this for them as nurses. The initial reasons for choosing learning disability nursing as a career formed a key theme within the findings, with complex influences on their career choice. Additionally, all participants in this study created a narrative of change, focusing on the ways in which change in policy, practice and in societal views have impacted upon their working lives and their identity. The individual narratives have also been interpreted to form a collective narrative of learning disability nursing to specifically explore the identity of learning disability nurses and nursing in a changing context of health and social care provision.

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## **Chapter 1 Introduction and Aims of the Study**

### **1.1 Introduction**

*There has been a revolution in the ways in which people with learning disabilities are both cared for and supported, and this necessarily has led to nothing short of a revolution to the practice of learning disability nursing.*  
(Gates 2011, p5)

There have been a number of influential factors that led to the undertaking of this study, including my professional background as a learning disability nurse who trained more than 30 years ago in a care context that was very different to today. The quotation from Gates (2011) above resonated with my experiences of learning disability nursing over a 30-year period, observing a seismic shift in not only the locations of care and support for people with learning disabilities but also the philosophical underpinnings of this care. At the beginning of this study in 2009 it had been 30 years since the recommendations of the Jay Report (1979) had suggested a move towards an altogether different model of care for people with learning disabilities and the demise of the learning disability nurse to be replaced by a worker based in social care. Learning disability nurses had been a key provider of care in an NHS-based system for those people who required support. My observation over the 30 years was that this role had changed, roles had been challenged, reconfirmed and redefined and the professional identity of learning disability nurses had been impacted on by these changes. A driver for undertaking this study was a curiosity in how these changes had shaped the professional identity of the learning disability nurse. My own journey was an important influence as I was aware this was also shaped by these changes in policy and services for people with learning disabilities over the past three decades. Being aware of my own position as a nurse would enable me to 'pay attention' to this within the research process (Holloway & Freshwater, 2007).

This thesis is underpinned by the view that learning disability is largely socially constructed and this will be discussed later in the thesis. Social and health policy

have defined and redefined learning disability nursing since its inception and in the past 30 years this has dramatically changed the meaning of nursing in this field of practice. But what impact does this have on the individuals who work as nurses within these services, on society, and the views around learning disability nurses? Understanding the history of learning disability nursing over the past 30 years enables us to see how society has constructed the meaning of learning disability, of community care and of learning disability nurses.

## **1.2 Models of service delivery for people with learning disabilities**

With the social construction of learning disability in mind, it is important to consider the ways in which society has 'cared for' people with learning disabilities, as this in turn has impacted on those who chose to work with people with this group.

The history of learning disability goes back as far as we have been able to write about the human condition. In pre industrial times it is suggested that people with learning disabilities were often part of communities where literacy and numeracy were not a necessity or priority. As such 'services' for people with learning disabilities in any formalised structure did not exist. During the Victorian era the rise of the institution brought with it a range of views and beliefs about people with learning disabilities. Not only did the institution provide society with an opportunity to remove 'undesirable individuals' from society, but also the opportunity for segregation of the sexes and the stifling of human rights for people with learning disabilities.

The notion of community care and maintaining people within their own homes rather than providing residential care has been spelt out since the early 1950s, even though socio-demographic changes suggest changing family structures will lead to declining numbers of potential care givers (Allsop, 1995). One of the attractions of community care for the Government may have been that it appeared a cheaper model, but this was also supported by a societal view that community care was a more appropriate on 'humanitarian and moral' grounds (Royal Commission, 1957).

But, whilst public support for community care for the elderly grew in the 1950s, the numbers of people in 'sub normality' hospitals continued to rise. Perhaps due to

ongoing eugenic views of many leading policymakers, not only did the institution provide society with an opportunity to remove 'undesirable individuals' from society but also the opportunity for segregation of the sexes and the stifling of human rights for people with learning disabilities. Eugenic concerns in the early post-war years supported the continuation of segregation for people with learning disabilities.

The development of community care for people with learning disabilities led to a number of related policy statements, including the Report of the Royal Commission (1957). This report recommended a parallel system of residential care, set up by local authorities, utilising small residential units of 20-30 places for people with learning disabilities. Politically this was supported in a speech by Enoch Powell, then Minister for Health, in 1961 advocating the 'run down of mental hospitals'. Although this could be seen as an economic move for the Government, the Minister's view was supported by sociological research into the conditions within institutions which described them as dehumanising environments with routines and structures that diminished the quality of life for those who lived there (Goffman, 1961). The conditions in institutions were picked up by a number of Inquiry's further discussed in chapter 2 of this thesis.

Whilst proposals for the development of residential units in the community were being suggested, a number of writers were proposing structures to divide those deserving of community care from those who were not. Dutton (1963) had proposed the division of people with learning disabilities into three distinct groups based on ability, with only the 'top stream' being suitable for a move to the 'community'. Galloway and Garrett (1964) also advocated the grouping of individuals based on ability, suggesting three groups, those who required nursing care who would stay in the hospital system, those who needed control within a secure environment, and those who required 'social training' for whom community living was advocated. Despite the debate over who should live within the community and how this should be decided, much of the care during the 1970s remained hospital based, following a medical model.

However, public inquiries into abuse within institutions during the 1960s and 1970s (Howe report, 1969; Spencer et al, 1978) fuelled concerns about the appropriateness

of institutional provision. Ham (1992) suggested that the Ely Hospital Inquiry led to major policy change within learning disability and contributed to the 1971 White Paper Better Services for the Mentally Handicapped (DHSS, 1971). It has been suggested that this was the first time changes in official policy were underpinned by clearly defined principles, reflecting current thinking about people with learning disabilities (Mitchell, 2000).

An element of the thinking underpinning the White Paper recommendations was rights based, supported by the 1971 United Nations Convention on the Rights of Mentally Retarded persons (United Nations General Assembly 1971 in Wolfensberger et al, 1972). Many argued that the White Paper, without the force of legislation behind it, would not put pressure on the providers of services (Race, 1995). Following the White Paper, Local Authority provision increased, but only a small number of hospital beds were reduced. This may have been due to Local Authorities increasing Day Services, not residential provision, as this could provide for larger numbers and was cheaper. The review also re-emphasised the need for joint planning of services between local Authorities and Health. This brought with it its own complications, and, in many areas, this is still not resolved some three decades later.

The Committee of Inquiry into Mental Handicap Nursing and Care was set up in 1975 under the Chairmanship of Mrs Peggy Jay with the task of examining the staffing of mental handicap residential care settings in the NHS and Local Authorities (Jay, 1979). The report findings have been described as radical (Rose, 1993), calling for the acceleration of community care, for an increase in staffing numbers and for management organisation to be streamlined. The Jay Committee report (Jay, 1979) carried a recommendation for the banning of any new construction or expansion of hospitals of 500 beds or more and a suggestion to increase Local Authority residential accommodation. Limited funding was available for this, however, and, where local authorities had a choice, many opted for the building of adult training centres which could provide for larger numbers than the small residential accommodation.

The Committee also recognised that the problems of institutionalisation were not confined to large isolated hospitals but could also manifest in small residential accommodation. 'A purpose-built unit in the edge of town is not in our view 'in the community'.' (Jay, 1979, p.36). It is suggested that the Jay Committee is one of the few documents that has reflected a shift in philosophical approaches to the care of people with learning disabilities (Wolfensberger, 1983; Race, 2002; Mitchell, 2003). In the same year that the Jay committee reported Mittler produced his key text '*People not patients*' (1979) linking rights for people with mental handicaps to the provision of appropriate resources, advocating the use of specialist resources within communities and 'better training for all staff who come into contact with disabled people' (p10).

With this background, the development of community care policies for people with learning disabilities occurred in conjunction with changes in philosophies of care for this group. The move towards deinstitutionalisation had already begun and government policies of community care were seen to be supporting these moves. Notions of rights of individuals, empowerment and choice were all seen to be in line with current policy. Community care policies were also underpinned by the development of philosophies of normalisation (Nirje, 1973). As the concept developed, its definition began to include the enhancement of socially valued roles for people with learning disabilities (Hattersley, 1991). Wolfensberger, in 1983, used the concept of 'socially valued roles' to formulate a change to the concept of normalisation which he named 'social role valorisation' (SRV). He argued that achieving socially valued roles in society would enhance the image and therefore acceptance by the non-disabled society of people with learning disabilities. The main means of achieving socially valued role would be the 'fitting in' of people with learning disabilities into the dominant value system within society.

A number of issues arise from this adoption of the principles of Social Role Valorisation (SRV). This perspective and that of normalisation appear to advocate values based on western culture, reflecting capitalism, materialism, competitiveness, individualism, and success of achievement within a nuclear family (Ni Ong, 1993). These values may require challenging and the views of people with learning disabilities should be sought to be certain that these are values that this group wants

to aspire to. The danger in not doing this is that normalisation and SRV may come to represent a lifestyle valued by its exponents but not people with learning disabilities (Bayley, 1991). A fundamental issue relating to normalisation and SRV is that the route to acceptance in society for de-valued groups is seen through some kind of normality (Ryan and Thomas, 1980; Corbett, 1991), a concept that is ambiguous and constructed by dominant groups in society.

In relation to policy formation, the concepts of power and normality are important. Foucault (1977) links these together in suggesting that normalising tendencies (an example of normalising tendency is the idea that paid work is a prime moral value) are powerful and ever present in society, whatever policies are in use at that time. Many services for people with learning disabilities have used the principles of normalisation and SRV without challenging the values they reflect. Institutions can exist in the community and, sadly, life in group homes and day centres may also mean being at risk from victimisation and abuse at worse (Philpot and Ward, 1995), or, for many, community care can mean loneliness and isolation as social networks are often limited (Flynn, 1989). Many people with learning disabilities who live independently or semi-independently live in poverty, with no opportunities for employment. It is arguable that the values of materialism and financial independence held highly in our society are unachievable due to social circumstance rather than the individual's learning disability.

Services, which have challenged the dominant community model, such as L' Arche, and Rudolf Steiner-inspired facilities, have contested whether roles valued by a particular society are appropriate for people with learning disabilities (Bayley, 1991). These 'alternative communities' have philosophies that acknowledge the unique contribution of people with learning disabilities to society, reflecting the stance that normalisation principles may disregard the right of people with learning disabilities to be different. Dalley (1992) has made the contrasts between normalisation and current social welfare ideologies - the notion of securing full rights for devalued citizens within the philosophy of normalisation is linked to collectivism, but there is a dichotomy, as the supporting of the status quo favouring family of quasi-family models of care and advocating competence and self-reliance are individualistic. It is

argued by Dalley that this is intrinsically damaging for people with learning disabilities:

Historically, therefore, people with learning disabilities have been at the mercy of society's view of them, the policies that are implemented, and models of service delivery adhered to, often with little opportunity to make choices for themselves. It is clear though that, since the inception of the NHS, even with the development of policies of community care that, as Race states, 'power over the learning disability agenda has remained in the hands of the Department of Health. (Race, 2002, p.35-6).

The models of care dominated by the NHS brought with them a group of workers based on the NHS model: nurses, doctors and nursing assistants who have been key in maintaining the medical model, even though the roles of these workers within the system have been consistently challenged. Understanding where learning disability nurses have come from historically, and the service models in which they work, is an important part of this study.

### **1.3 The impact of changing service models on the learning disability nurse's role.**

My journey into learning disability nursing started at an early age when I worked voluntarily with children who had complex disabilities and were staying in the respite care environment, where I volunteered. My passion for working with people with learning disabilities continued as I undertook nurse 'training' in a large long-stay hospital and faced challenges on a daily basis to the way I felt care should be delivered. Over the years I worked with many nurses who, like me, were constrained by an environment of routine and order, one which often disempowered both the nurses and those that lived in that environment. However, I was also supported in this environment, feeling part of a 'community' and feeling privileged to share the day-to-day lives of people with learning disabilities. I began my nurse training in the early 1980s at a time when there had been a major challenge to the role of the learning disability nurse from the Briggs report (1972) and the Jay Report (1979). The Briggs report had suggested a new professional grouping and Jay had suggested replacing nurses with workers who held a social care-based qualification. Each decade post Jay brought with it a challenge to the role of the learning disability nurse. A letter from the Chief Nursing Officer (CNO) in 1985 reinforced the

commitment to maintaining the role and status of the learning disability nurse (Mitchell, 2000). The 1990s also brought with it a change in the emphasis in role of the learning disability nurse, the Cullen report (1991) suggested a greater emphasis for learning disability nurses on the health rather than social care needs of those with learning disabilities - a move towards health - and this has been further supported by a number of reports as the focus on the role of the nurse has re-emerged in health. This focus has been reinforced by a number of reports that have acknowledged the health needs of people with learning disabilities who have moved from institutions and into community-based living.

With this background, learning disability nurses have been debating their role within the nursing profession since (Mitchell, 2003). Some 30 years later, in 2001, the Government produced its White Paper Valuing People First (DH, 2001) where there is little mention of specific services, but the notion of inclusion and the use of generic services is clear and part of the guiding principles of this White Paper.

Although still a discrete branch of nursing, the debate around the future of the learning disability nurse still rumbles on. A wide range of service provider agencies, and inclusion being the key principle for people with learning disabilities in society, has left some doubt over the future role of the learning disability nurse. The impact of this debate is not only upon service provision but also on the future education of learning disability nurses. Mitchell's (1998; 2000; 2002a; 2003) work has examined the link between social policy, service provision and education. This study is located within this context and develops further the work of Mitchell to examine current Government policy (Post Jay Report) to include key policy documents and reports – Continuing the Commitment (DH, 1996) Signposts for Success (DH, 1998); Valuing People (DH, 2001); The Health & Social care Act (DH, 2003); Choosing Health (DH, 2004); Our Health, Our Care, Our Say (DH, 2006), and the potential impact on service provision and the future of learning disability nursing and education. The narratives of learning disability nurses within the study will contribute to an understanding of the impact of said policies upon the lives and careers of learning disability nurses in England in the past 30 years.



A gradual philosophical shift following the work of O'Brien (1981), Wolfensberger (1983) and Nerje (1972; 1985) was also being observed (at least in the confines of the classroom). These theorists were advocating different lifestyles for people with learning disabilities based on human rights, living lives that were as close to 'normal' as possible (normalisation) and setting out 'accomplishments', such as choice, community presence, relationships, competence and respect. However, the institutions where people lived continued to constrain by their very nature. Soon after qualifying as a registered nurse I worked in a small-scale community-based residential unit with children who had complex and life-limiting disorders, managed by the same hospital in which I had undertaken my training. My observations at this time were that many nurses were struggling with the move from the large long-stay hospital to small community-based services and the level of change that this brought with it. Nursing within small quasi-family structured environments, after being part of large multi-bedded wards in large long-stay hospitals, brought its challenges for staff and for people with learning disabilities themselves.

Learning disability nursing at this time was also being questioned in terms of its place in this new care philosophy (Barr & Sines, 1996 ), care was being provided in Local Authority settings and in many areas the development of community nursing teams to support people in their own homes was in its infancy. This period of uncertainty prior to the 1990 NHS and Community Care Act (DH) felt like an unsettled time for learning disability nursing. I had an opportunity to work in what was then a college of nursing, managed by the health authority, as a clinical nurse teacher delivering nurse education. Retaining my links with nurses working in large long-stay hospitals as I supported students undertaking placements in these areas, I was also aware that many had begun to work outside of the NHS supporting people with learning disabilities.

For a decade or more the move towards the closure of long-stay hospitals moved rapidly and, whilst some provision was still being provided by the NHS, this was of a specialist nature and small numbers comparatively. In my role in education, preparing learning disability student nurses, I saw a decline in applications and in interest in the field of nursing as worries over whether there would be a job as a nurse at the end of the course became pronounced.

Since 2008 there had been a steady decline noted in the numbers of learning disability nurses, arguably as NHS campus bed numbers have declined, so have the numbers of nurses. However, one might expect to see an increase in the numbers of community nurses as the numbers of people with learning disabilities living outside of NHS provided hospitals increased. Emerson and Glover (2012), however, highlight the numbers of these nurses have dropped - *'Numbers of community nurses change little from 2008 to 2009, rise by three per cent to 2010 and then fall by 16 per cent to 2011'* (Emerson et al, p.195). Whilst they suggest that 'this trend is less easy to explain', this could be due to the number of learning disability nurses who work in diverse settings in the community but who do not hold the specific title of 'community nurse'. Locating learning disability nurses at this time was becoming increasingly difficult as a range of titles for roles existed and many roles sat outside of NHS provision in school, prisons, residential settings, acute hospital trusts and the independent sector. However, Emerson and Glover reported that, whilst it is acknowledged that there is a large shortfall between the numbers of nurses registered and those accounted for in workforce statistics - some 12,433 - these cannot be reasonably accounted for by employment in the independent sector. Emerson and Glover draw on Gates' statistics from the 2011 report, suggesting that 'at least 2,500 were working in independent sector facilities of some type' (Gates, 2011). Gates (2011) reports:

It is known that the numbers of learning disability nurses employed in the NHS has continued to fall year on year from 12,504 in 1995 to 6,600 in 2009 [something in the order of a reduction of 53%] or ~1,000 a year, with a reducing participation rate that has fallen by 3.9%, and a growing vacancy factor from 2008 [1.3%], 2009 [1.7%] and 2010 [2.0%]. (National Health Service, 2010, p.8)

A small proportion of this large shortfall in learning disability nurses could be accounted for by workforce statistics. Emerson and Glover (2012) offer a number of suggestions for the decline in learning disability nurses in their work, however, there is no current solution to the difficulties of accounting for learning disability nurse numbers across a diverse range of potential employment settings.

The range of settings in which learning disability nurses work provides challenges in undertaking research with this group. It is acknowledged by many that there is some difficulty in identifying the numbers of learning disability nurses in employment - there are figures around student places held by HEIs and commissioners, and figures held by the Nursing & Midwifery Council (NMC) of those that are entered onto the Register, but, beyond this, the data is at best patchy both in its accurate collection and in its ability to reflect those nurses who work outside of the NHS.

Recent studies have focused on the declining numbers of learning disability nurses and their places of employment. Gates, in 2010, was commissioned to Chair a task and finish group examining a number of questions raised via the professional advisory board to the English Department of Health around learning disability nursing, including examining the diminishing numbers of learning disability nurses, exploring the service modules in which they practice, and 'identifying the national supply and demand for learning disability nurses, including the number of student places commissioned' (Gates, 2011, p.4). The report, published in 2011, concluding:

The task and finish group conclude that learning disability nursing has moved from a narrowly defined role, within long-term care, to a much broader role within the National Health Service and beyond. It is a health profession supported and endorsed by many as unique in its breadth of employment base, located as it is among the various sectors. Learning disability nursing roles span community support specialists, liaison roles between services and agencies, and roles in secure or forensic health settings, and these roles offer support across the age continuum. (Gates, 2011, p.3)

More recently, the Chief Nursing Officers (CNO) of the four countries of the UK reviewed learning disability nursing, with their report echoing Gates' work in suggesting that: 'learning disability nurses work in many different settings, including community teams, some inpatient services, criminal justice and education contexts and, to an increasing extent, independent/voluntary sector settings' (UK Chief Nursing Officers, 2012 p.2).

Changes in the nature of the role of the learning disability nurse towards a more diverse range of activities and the places in which learning disability nurses practice suggested to me that these nurses, more than in any other field of nursing, had extended and expanded their location of professional practice, adopted new ways of

working, and embedded themselves within a wider range of professional and non-professional groupings. Understanding how learning disability nurses perceive their careers and their identity at a time of change or 'revolution', as Gates suggests, became, for me, a desirable focus of study.

There have been few studies which focus on working lives of learning disability nurses in a historical context, and, uniquely, this study uses a narrative approach to understanding why they chose learning disability nursing, and their experiences of being a learning disability nurse. The present study adds to the literature around career choices in nursing and around the professional identity of learning disability nurses at a time of change.

#### **1.4 Aims of the study**

The overall aim of this study was to gain an in-depth understanding of the lived experience of the careers of learning disability nurses in England over the past 30 years. In order to achieve this, further sub aims were developed to explore the reasons for choosing learning disability nursing as a career and gain an enhanced understanding of the working lives of learning disability nurses. Underpinned by hermeneutic phenomenological principles, a narrative approach has been taken to explore the participants' experiences. An adapted approach to Biographical Narrative Interpretive Method (Wengraf, 2001) was used to frame the interview processes and enable an 'open' approach to generating narrative. The study gained research ethics approval from De Montfort University Ethics Committee and a request for learning disability nurses to take part in the study was posted on a variety of online 'networking' sites in order to capture those nurses working outside of the NHS. Twenty learning disability nurses across nine counties of England were interviewed in two-stage interviews that ranged between 90 minutes and two hours long, with a thirty-minute break, as part of the BNIM interviewing process. The participants were offered further follow-up interviews, typed transcripts were shared for checking and pseudonyms were chosen. The transcripts of these interviews created both a rich individual narrative and also a collective narrative of learning disability nursing which were analysed using narrative analysis.

## **1.5 Thesis structure**

The thesis is organised around the following structure:

Chapter 2 examines the literature around learning disability nursing, career choices, identity and the working lives of nurses, in order to contextualise the study and its aims. The literature relevant to this study is from a diverse range of health and social care literature and incorporates a historical view of learning disability nursing in order to locate the issues. Chapter 3 offers a detailed exploration of this study's methodological approaches, outlining the philosophical underpinnings and practical application of the narrative inquiry. Chapter 4 is the first of three chapters detailing the findings of the study. It contains the 'cameos' of the 20 participants engaged in the study. As part of the analytical process, these 'cases' were generated in order to analyse the themes within each narrative prior to examining themes across participants. Taken with field notes gathered at the time of the interviews, these form the 'case' on which analysis is based. Chapters 5 and 6 provide an analysis of the themes arising from the participant narratives, including career choice, working lives and identity. The participant 'voice' is an inherent part of these chapters as their words become quotations and these are analysed in relation to the themes arising from the interviews. Chapter 7 draws together these themes into a critical discussion and highlights the study's unique contribution to knowledge in the field. As a unique study in the UK utilising a biographical narrative approach in order to explore the motivations towards learning disability nursing and the working lives of learning disability nurses over a 30-year period, the study adds to the extant evidence base informing education, practice and research. The final chapter provides a reflection on the research process, discusses the study's limitations and explores implications of the study's findings for education, practice and research.

## ***Chapter 2: Literature Review***

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### **2.1 Mapping the process**

In order to understand and locate literature pertinent to this study in a systematic way, a literature review was undertaken utilising a framework that enables a rigorous review of the literature to avoid bias (Aveyard, 2010; Hart, 2003). This framework included a clear identification of the research question; focused search strategy and appraisal, and synthesis of the material to ensure rigour and validity in the literature review process. In common with many qualitative studies, my research question was framed within an aim for the study; to explore the lived experience of the careers of learning disability nurses in England over the past 30 years, the motivations for becoming a learning disability nurse, and their professional identity. Three key areas became the focus of my literature review; firstly, the history of learning disability nursing, its location and practices; secondly, what motivates people to become nurses and, more specifically, learning disability nurses, and, thirdly, identity and nursing, providing parameters for my search strategy. I was aware that there had been two key literature reviews undertaken by Northway et al in 2007 and, a year later, Griffiths and others 2008 undertook a large-scale review which suggested that:

The extent of learning disability nursing research is limited in quantity and it is difficult to draw comparisons across research studies. Much of the available evidence is drawn from small-scale evaluations; which may provide useful guidance and inspiration for service development but do not, in themselves, constitute a sufficient body of research evidence to support learning disability nursing practice. (Griffiths et al, 2008, p.490)

Whilst acknowledging the limitations suggested by Griffiths et al (2008), the purpose of the literature review was to understand the literature that already existed relevant to the research area and the potential for this study to build on this literature base, and make an original contribution to knowledge through the exploration of the working lives of learning disability nurses.

Searching the research base around learning disability nursing is complicated by the use of a wide range of terms across the international literature including, in the UK alone, learning disability, learning difficulty and intellectual impairment. These terms

may sometimes be used interchangeably but they may also describe very different groups of people internationally. In the US Mental Retardation is a common term used and, until recently, in the UK this has been mental handicap. Additionally, education-focused literature may also use the term learning difficulty or learning difference to describe a completely different group of people, those who have conditions such as dyslexia and ADHD who do not have a learning disability. As described in chapter 1, the definition of learning disability underpinning this study was constantly referred back to in the literature search process to ensure relevance. The literature search incorporated a broad database search, beginning with CINAHL PLUS, BNI and ASSIA, but also cross-checking these searches with a ProQuest search including six databases; ASSIA, Periodical Archive Online, ProQuest Dissertation & Theses UK & Ireland, Pro Quest Psychology Journals, PsycArticles and PsycInfo. Appendix 1 outlines the search results, including search terms and 'hits'.

The number of 'hits' in some databases reflected the breadth of the use of the keyword learning disability, and also its relevance in an international context with the term in some countries referring to a wider more diverse group, including those with dyslexia, dyspraxia and other conditions impacting on learning. This was countered with the filtering through keyword searches to reduce the numbers of irrelevant hits. The broad search terms of learning disability/mental handicap/intellectual disability or mental retardation and nurses/nursing produced a breadth of literature, so titles were scanned for relevance and to place the literature into categories for further scrutiny. Further searches used the following search terms: Career choices and learning disability nursing/nurses professional identity and learning disability nurses/nursing (see appendix 1).

Whilst initially focusing on the published literature, 'grey literature'; unpublished material including unpublished theses and conference proceedings, were also included in the search parameters to ensure maximum access to what is a limited research base. Specific inclusion criteria of date and of publications written in English also ensured that the literature was as specific as possible to my research area. Whilst the study was based in England, the examination of the literature included other countries to contextualise learning disability nursing globally.

Examination of the chosen literature enabled further searches using what is described as the snowballing effect, finding literature cited in the original sources (Averyard, 2010). References were all collated into an electronic research bibliography using a reference management system 'Refworks' ® [www.refworks.com](http://www.refworks.com) enabling me to create themes from the search, annotate studies and organise the material.

My initial interest was to examine the period of 30 years from the early 1980s; however, in order to understand the changes during that period and to set the scene for the research the initial literature review was set for those database searches which allowed it to 1960. Earlier articles were also reviewed if found in studies through a method of hand searching and deemed relevant. Additionally, as the study focuses on the working lives of nurses, the breadth of the literature search needed to include elements of working lives rather than just a chronological history of the development of learning disability nursing.

The search yielded similar results to those published reviews of the literature by Northway et al (2007) and Griffiths et al (2008). There was a wide range of literature which, for the purposes of this study, was sorted into that which focused on the specific history of the learning disability nurse from a first-person perspective (Gates & Moore, 2002; Jukes, 2011); the history of learning disability services; and the place of the nurse within these services.

Surprisingly, there were few research studies focusing specifically on the working lives of learning disability nurses in the UK in a historical context, notably Gates and Moore, (2002) focused on the working life of one learning disability nurse, Annie and Jukes (2011) offers a semi-autobiographical account of his career over a 30-year period, beyond this the literature focuses within wider studies on the nurses' role and function in the context of a 30-year period. Additionally, much of the published literature does not constitute published research, as much of the literature in this area was found to be commentary from learning disability leads in the field rather than the results of specific research studies. This, however, remains important to my study as it often describes learning disability nursing from the perspective of leaders in the field and those who have contributed to the extant literature base.



Whilst commentators in the field reflected upon the roles of the learning disability nurse, the literature review enabled a historical overview and timeline. It was expected that more of the published work would have a focus specifically on the working life of the learning disability nurse from their perspective. It is this particular gap in the literature where my study will contribute to the existing body of knowledge and make a unique contribution in using the voices of 20 learning disability nurses through a biographical narrative approach.

The literature focused around career choice in learning disability nursing is fairly limited, whilst there is a broader research base around nursing more generally. Additionally, the search for 'professional identity' and 'learning disability nurses/nursing' produced few results, whilst the search term nursing produced thousands of hits and required further keyword filters (appendix1).

The literature search results were minimal from the learning disability nurses' narrative perspective, however, the history of learning disability nursing, the role and function of the learning disability nurse, and the development of services have been debated in the literature and a large proportion of this is written by learning disability nurses themselves. In addition, the shaping of the services in which learning disability nurses work has been documented alongside policy change and the influence of these changes upon working practices in learning disability nursing. In the next section of this chapter the literature will be critically reviewed in the context of my research aims, to take a look at the history of learning disability nursing in order to examine the working lives of learning disability nurses over the past 30 years, their career choices and their identity.

## **2.2 Care for people with learning disabilities: a historical context**

Formalised health and social care services are relatively new in historical terms, however, people with learning disabilities are not a new group within society and have existed in documented records for thousands of years. A number of commentators have explored the history of learning disability as both a condition and social construct, examining the historical response of society to those who over the years have had many different labels, reflecting the prevailing societal attitudes of

the time. These secondary sources of historical information will provide a context for the development of care for people with learning disabilities and the place of the learning disability nurse within that. Understanding the place of people with a learning disability in our society is an important precursor for understanding how the profession of learning disability nursing came to exist, the places and institutions in which this nursing took place, and the changes that have taken place in the past 30 years. Emerson (2005) suggests that the way in which people with learning disabilities in society are treated is based on three main underpinnings: 'Public and professional preconceptions of the nature of learning disability, notions of common decency and pre-existing mechanisms for the delivery of welfare support' (p.109). This is reflected in the changing nature of care provision and welfare for people with a learning disability in England, and the literature which illustrates these changes.

In *Critiques of Segregation and Eugenics*, Richardson (2005), examines pre-industrial society and its approach to people with learning disabilities, asserting that written accounts of difference based on disability are 'largely absent [...] since in pre-industrial societies only the wealthy and ruling classes were likely to be educated and literate' (in Grant et al, 2005, p.67). He goes on to suggest that, where history does focus on those with a physical or mental disability, this is at the extremes of either 'exclusion' or 'veneration'. The example of those labelled village idiot is relevant here, where in pre-industrial societies those we now recognise as having learning disabilities were often an accepted part of a community, the label 'village idiot' was one which acknowledged the person's place within the community (albeit within their own grouping of deviants) in addition to their social and later legal label of 'idiot' (Richardson, 2005).

Industrialisation changed the place of people with disabilities in society as capitalist ideology impacted upon social stratification. Difference was the key to capitalism's need to 'remove, control and discipline those who would not or could not conform to new working practices by demanding greater secular controls' (Richardson, 2005, p.71). As such, this period of industrialisation and its focus on contribution to society through capitalist enterprise heralded growth in institutional settings for the 'sick poor', many of whom we might now describe as having learning disabilities. McClimens (2005) describes the 1601 Poor Law Act as an 'early example of social

policy' (p.29) as the recognition of those who may need additional support following difficulties in the local economy and the classification of those into the 'deserving poor' were embedded in the premise of this Act. Whilst at this time people with learning disabilities were not identified as a specific group in this early classification, McClimens suggests 'the origins of targeted care were beginning to emerge in the provision of poor relief' (p.29). Understanding the early history of classification is an important aspect of my study as it locates the person with a learning disability in society and sets the scene for the nurses who were eventually involved in their care

This focus on classifying and then 'caring for' the sick poor continued; Richardson in his account, states that: 'Between 1720 and 1825, 150 hospitals were built in England to cater for the sick poor' (2005, p.71). This growth continued with the development of 'idiot asylums' with upward of 500 beds supported by legislation in the Idiots Act of 1886, placing the emphasis on local authorities to provide these services. As early as these asylums were built there were concerns raised about the treatment and regimes within them. By 1845 the Insanity Act had ensured a Medical Superintendent was in place in all asylums, heralding the medicalisation of what had previously been seen as a social issue. Growth in the field of psychiatry had also placed emphasis on mental disorders as medical conditions, and therefore potentially 'treatable'. As a result of this, many people with learning disabilities were housed in these institutions alongside those with psychiatric disorders (Ryan & Thomas, 1980). Following the 1845 Insanity Act concerns were raised around overcrowding in institutions, resulting in the Lunacy Amendment Act (1862) enabling movements between Workhouse and Asylum to deal with the issue.

In 1886 the Idiots Act provided a distinction between what were known as lunatics, idiots and imbeciles, categorising those we now label as having mental health problems as 'lunatic' and those categorised as Idiots and Imbeciles (those we now label as having learning disabilities) and examined the educational needs of those who were defined as idiots and imbeciles (McClimens, 2005; Barber, 2012). Alongside the medicalisation of such conditions, educational theorists were at this time also suggesting that 'training' could enhance the potential of those with learning disabilities. These distinctions are important within the historical narrative presented here as they impact on services for those categorised in particular ways. Those with

what we now define as mental health problems were categorised differently to those who have a learning disability, leading the way for a separation of services for those with these conditions.

McClimens (2005) in his historical account *From Vagabonds to Victorian Values: The social construction of disability identity*, suggests that concerns over the conditions within the institutions led to the Royal Commission on the Care and Control of the Feeble Minded 1904-08 (The Radnor Report), the findings of which 'paved the way for the Mental Deficiency Act of 1913' (Barber, 2012, p.191). With a clear focus on the genetic inheritance of disability, The Radnor report led to the incarceration of thousands of people with learning disabilities ('mental defectives' at the time) in 'colonies' set up specifically for this purpose (Ryan & Thomas, 1987). The language used in society at the time in reference to these colonies was also important. People were 'detained' for life (Ryan and Thomas, 1987, Barber, 2012), suggesting a punishment approach to having a learning disability and eugenic concerns about the future of society.

The literature describing the history of care for people with learning disabilities post-industrialisation is bleak. Eugenicist discourse constituted a powerful force, encouraging the incarceration of thousands of people with learning disabilities in the UK and supported legally through the introduction of the 1913 Mental Deficiency Act. These medicalisation ideologies and legal frameworks also began a labelling and categorisation process for people with learning disabilities who, within the 1913 Act, would be determined 'feeble minded', 'idiots', 'imbeciles' and 'moral defectives'. These categories were also used to determine who would receive education, as the feeble minded in particular were thought to be a group that might benefit from such provision. A number of scholars describe the Act as one stemming from the eugenic aim to remove and segregate from society those seen as 'different' and therefore undesirable (Richardson, 2005; Ryan and Thomas, 1980; Barber, 2012). Theories of eugenics in the late 1800's and early 1900's were largely built from theories of genetics and inheritance, based on plant reproduction and the transference of characteristics between generations.

Subscribing to this belief system fuelled a view that *'feble-mindedness was a genetically inherited disease that would eventually reduce the nation's intelligence'*

(Richardson, 2005, p.73). This was further strengthened by the growth in views that disability equated to social deviance and the questioning from an economic perspective the value of disabled people in society.

As a result of this, people seen to be feeble minded were often removed directly from communities and incarcerated with or without their or their families' consent. The Eugenics movement played a powerful role in the development of institutional care for people with learning disabilities between World War I and II and in the years immediately following as those contributing to policy at the time advised Governments on the care of people with learning disabilities. Emerson (2005), in his chapter 'models of service delivery', quotes Tredgold, a leading psychiatrist advising a variety of commissions, in 1909 who stated:

I have come to the conclusion that, in the case of the majority of the feeble-minded, there is one measure, and one measure only...which is practically possible, namely the establishment of suitable farm and industrial colonies.... society would thus be saved a portion, at least, of the cost, of their maintenance, and more important, it would be secure from their depredation and danger of their propagation. (Tredgold 1909 in Emerson, 2005, p.113)

These views were supported by Government at the time and the subsequent 1913 Mental Deficiency Act made clear delineation between the care of those with learning disabilities and those with mental health problems (Emerson, 2005). Influenced largely by eugenic views of the time, people with learning disabilities were seen to require incarceration and segregation rather than the treatment required by those with mental health problems. This period in history is very relevant to the history of learning disability nursing as it reflected care models, including large institutions which later became hospitals staffed by learning disability nurses. By 1919 the Nurses Registration Act had been approved and the General Nurses Council (GNC) had a separate part of the register for mental deficiency nurses. Prior to the inception of the National Health Service, the training of those working with people with learning disability (then known as mental deficiency) had been based in the large institutions, colonies or private institutions caring for those with learning disabilities and mental health problems. Initially, training had been alongside that of psychiatric medical superintendents with accreditation through the Medico Psychological Association and reflected the 'care' received by people with learning

disabilities at the time. They were cared for alongside people with mental health problems and social deprivation often resulted in them being institutionalised. However, after the 1913 Mental Deficiency Act the incarceration and segregation of people with learning disabilities was deemed 'different' to those with mental health problems and, as such, required its own workforce (Mitchell, 2000). Mitchell also suggests in his historical study of learning disability nursing that 'mental deficiency nursing became part of the nursing profession because of a series of coincidences of timing and group interest. The GNC (General Nursing Council) was unable to dislodge it because of interests involved in its continuation' (Mitchell, 2000, p.201). He argues that the place of nursing and therefore learning disability, or mental deficiency nursing at the time, was influenced by the need of the medical profession to control the work in institutions: *'Mental deficiency specialists had a vested interest in the establishment of a discrete group of nurses over whom they could exercise control'* (Mitchell, 2000, p.88) Whilst this landmark shift in the separation out of conditions relating to learning disability and those related to mental health disorders impacted on care, the work of the Eugenics movement continued between the two World Wars and Tredgold was influencing the education of medical professionals and nurses across the UK. His first edition of Mental Deficiency was published in 1908 and continued to be used for the next 50 years, with this damning quote still appearing in the eighth edition in 1952:

The 80,000 or more idiots and imbeciles in the country... are not only incapable of being employed to any economic advantage, but their care and support, whether in their own homes or in institutions, absorbs a large amount of time, energy and money of the normal population which could be utilised to better purpose. Moreover, many of these defectives are utterly helpless, repulsive in appearance, and revolting in manners. Their existence is a perpetual source of sorrow and unhappiness to their parents, and those who live at home have a most disturbing influence on other children and family life... In my opinion it would be an economical and humane procedure were their existence to be painlessly terminated. (Tredgold 1952 in Emerson, 2005, p.113)

Whilst many may be shocked today at views such as Tredgold's, philosophies underpinned by beliefs such as this were reflected in the care provision for many people with learning disabilities in large long-stay institutions but also in their exclusion from society. Following the enactment of the National Health Service

(NHS) Act in 1948 in Britain, and the establishment of health services which were free to all at the point of delivery, the institutions in which people with learning disabilities lived became part of the NHS and, by the early 1950s, the General Nursing Council (GNC) had taken over the training of those nurses working within these institutions. However, records examined by Mitchell show that as early as 1926 the status of these workers as nurses was being questioned, as it was clear they did not 'care for the sick' (Mitchell, 2002). However, this might be expected as the history of care of people with learning disabilities up to the early 1920s was underpinned by philosophies of segregation, exclusion and custodial provision.

This challenge to the status and value of the learning disability nurse continued, and in 1979 the Jay Committee put forward two key policies supporting the move away from nurses supporting people with learning disabilities. Prior to the Jay Report, the Briggs Report in 1972 had suggested a new professional grouping, while Jay had recommended replacing nurses with workers who held a social care-based qualification. The Committee of Inquiry into Mental Handicap Nursing and Care was set up in 1975 under the Chairmanship of Mrs. Peggy Jay with the task of examining the staffing of mental handicap residential care settings in the NHS and Local Authorities. The report findings have been described as radical (Rose, 1993), calling for the acceleration of community care, for an increase in staffing numbers, and for management organisation to be streamlined. The Jay Committee report (DHSS, 1979) carried a recommendation for the banning of any new construction or expansion of hospitals for people with learning disabilities of 500 beds or more and a suggestion to increase Local Authority residential accommodation. However, only limited funding was available and, where local authorities had a choice, many opted for the building of adult training centres that could provide for larger numbers, rather than the small residential accommodation. The implications of this include a continuing focus on a medical model of care in a largely hospital-based provision.

The Jay Committee Report in 1979 not only redefined the structure of learning disability services in England, Scotland and Wales, but also the role of the learning disability nurse; suggesting that learning disability nurses should, over time, be removed from conventional nursing, to allow for the emergence of a new professional group. This fundamental shift in thinking provided a key challenge for

learning disability nursing as the then Government rejected the established models of service delivery in favour of a non-nurse-led model. This, along with subsequent reform in learning disability, was another important marker in the history of learning disability nursing acknowledged when undertaking this research study with the potential to shape how nurses see themselves and the services they work within.

Although rejected by the newly-elected Conservative Government, the Jay Committee Report had laid a foundation stone for reform in learning disability services that philosophically had already begun. The notion of community care and supporting people within their own homes, with families delivering the majority of care, had been around since the early 1950s, despite socio-demographic trends suggesting that changing family structures would lead to declining numbers of potential care givers (Allsop, 1995). One of the attractions of community care for the Government may have been that it appeared to be a cheaper model than large long-stay hospitals or residential provision. The community care model was also supported by a societal view that it was more appropriate on 'humanitarian and moral' grounds, as families took responsibility for the care of their members (Ministry of Health, 1956).

But, whilst public support for community care for the elderly grew in the 1950s, the numbers of people with learning disabilities residing in long-stay hospitals continued to rise. The need for the development of community care for people with learning disabilities led to a number of policy statements, including the Report of the Royal Commission (1957). This report recommended a parallel system of residential care set up by local authorities utilising small residential units of 20-30 places for people with learning disabilities. Enoch Powell, then Minister for Health, supported this politically in a speech in 1961 advocating the 'run down of mental hospitals'. Although this could be seen as an economic move for the government due to the perceived relatively lower cost of community care, the Minister's view was supported by sociological research into the conditions within institutions, which described them as dehumanising environments with routines and structures that diminished the quality of life for those who lived there. Describing the experience of someone on admission to an institution, Goffman suggests 'a series of abasements, degradations, humiliations, and profanations of self' (Goffman, 1961, p.24). Much of



Goffman's work focused on the negative aspects of institutions and influenced the development of community-based care (McClimens, 2005).

Whilst proposals for the development of residential units in the community were being suggested, a number of writers were proposing structures to divide those deserving of community care from those who were not. Dutton (1963) had proposed the division of people with learning disabilities into three distinct groups based on ability, with only the 'top stream' being suitable for a move to the community'. Galloway and Garratt (1964) also advocated the grouping of individuals based on ability, suggesting three groups; those who required nursing care who would stay in the hospital system, those who needed control within a secure environment, and those who required social training for whom community living was advocated. It could be argued that such recommendations carried with them echoes of the Poor Law Act, as the question of who was 'deserving' came again to the fore.

Despite the debate over who should live within the community and how this should be decided, much of the care during the 1970s remained hospital-based, following a medical model. However, public inquiries into abuse within institutions during the 1960s and 1970s fueled concerns about the appropriateness of institutional provision (Howe Report, 1969; Normansfield, 1978). In particular, the findings of the Ely Hospital Inquiry, which highlighted poor conditions for those who lived in the large long-stay mental handicap hospital in Wales, led to major policy change within learning disability care (Ham, 1992), contributing to the 1971 White Paper Better Services for the Mentally handicapped (DHSS, 1971). It has been suggested that this was the first time changes in official policy were underpinned by clearly defined principles, reflecting current thinking about people with learning disabilities and mirroring service models from across Scandinavia of small-scale community-based provision and the emphasis on behavioural change and potential for education espoused by psychologists of the time (Tizard, 1954; Malin, 1995). However, although the thinking underpinning the White Paper recommendations could be understood as rights-based and supported by the 1971 United Nations Declaration of Human Rights, Race (1995) argued that, without the force of legislation behind it, the White Paper would not put the pressure needed on providers of services to implement change. Peter Mittler in his work 'People not Patients' in 1979 advocated

a number of approaches to what he termed 'ordinary and special services' acknowledging the challenges but also family involvement in the planning of services and joint planning between health and social care services. Mittler also suggested the use of 'expert advisory' groups like the National Development Group 'to develop policies and the Development Team to help authorities to improve their services' (p.18).

Although local authority provision increased following the White Paper, only a small number of hospital beds were actually cut. This may have been due to local authorities increasing day services rather than residential provision, as this could provide for larger numbers whilst keeping down costs. In addition, the Jay Committee report had also recognised that the problems of institutionalisation were not confined to large isolated hospitals but could also manifest in small residential accommodation: 'A purpose-built unit on the edge of town is not in our view 'in the community'.' (1979, p.36). This is in keeping with Goffman's view of institutions, in that it is not the size but the routines and treatment within them that define them. The theme of institutionalisation and control within this context is an important theme when we consider the development of community care for people with learning disabilities, the location of services within a medical model, and the subsequent role of the learning disability nurse.

The place of the institution in the history of the learning disability nursing is significant. The post-war years continued to see a growth in institutional care for people with learning disabilities as society increasingly viewed those with disabilities as in need of incarceration and eugenic concerns were supported by policy decisions (Mitchell, 2001; Gates and Moore, 2002; Malin & Race, 2010). Hospitals controlled by medical professionals and employing large numbers of learning disability nurses were the focus of care for people with learning disabilities who were unable to live with their families. Many long-stay hospitals housed up to 1,000 people and were often the major employers in an area. Nurses practised within 'locked' environments, where conditions were described as inhumane for the people who lived there and a number of them became the subject of various investigations. Ely Hospital in Cardiff had been subject to an investigation following concerns about care from a staff member there (Drakeford & Butler, 2006). The popular press ran this story and, led

by the then MP Geoffrey Howe (Howe, 1969), the investigation uncovered a series of 'scandals' around allegations of ill-treatment of patients and financial irregularities (Drakeford & Butler, 2006). Farleigh Hospital Inquiry (DHSS 1971) and the Normansfield Hospital inquiry (DHSS1978) followed with similar themes around not only the treatment of patients (people with learning disabilities) but also concerns that staff had not received training and were not aware of new developments outside of the hospitals.

Both from a policy and public attitude perspective, the institution was once perceived to be an acceptable place in society for the care and containment of people with a learning disability. Today, institutions are seen to provide a negative space and landscape. Goffman (1968) outlines the characteristics of institutions and the totality of control over an individual's life, in that everything (work, play and sleep) takes place within the same environment, suggesting that this control is what makes institutions distinctive.

The impact of an institutional model of service provision upon learning disability nurses has been highlighted by a number of studies (Mittler 1979 Potts and Fido, 1991; Mitchell, 2002; Ryan and Thomas, 1980; Oswin, 1973; Gates and Moore, 2002). Gates and Moore (2002), in their study *Annie's Story*, highlight details of life in the institution both for those with learning disabilities who lived there, and also the nurses in terms of daily routines, relationships and care. A unique oral history study charts the story of Annie, a learning disability nurse practising between 1938 and 1981, identifying the impact of social policy and changing practice upon the role of the nurse. *Annie's Story* reveals a personal account of working life in an institutional setting which adds an authentic insight into the role and function of the learning disability nurse at this time. It is, however, limited in that it is a single case study. Many of the experiences of Annie described in the study by Gates and Moore (2002) have also been part of the shared experience of some of the nurses in my study. However, what is different is the focus in my study on 20 learning disability nurses whose careers span from the early 1960s through to the interviews in 2010. The 'post Jay' era after 1979 is marked with discussions around the future of learning disability nursing, the shape of services for people with learning disabilities in a community context, and the changing role of the learning disability nurse within this.

Although it is suggested that the Jay Committee report is one of the few documents that has reflected a shift in philosophical approaches to the care of people with learning disabilities (Malin, 2002; Malin & Race, 2010; Wolfensberger, 1983; Mitchell, 2000; 2003), it is the proposal to remove learning disability nurses from the care of people with learning disabilities that the report is often noted for.

### **2.2.1. Post Jay Report and the era of community care**

Each decade post Jay Report has brought with it challenges to the status and the role of the learning disability nurse in response to changing patterns of service delivery. The closure of NHS-funded hospitals and philosophies of normalisation led to opinion leaders and policymakers of the time recommending that the health care needs of people with learning disabilities should be met by generic rather than specialist services (Kings Fund, 1980; DH, 1989; DH, 2001). As such, the 1990s brought a change in emphasis around the role of the learning disability nurse, with many long-stay learning disability hospitals having either closed or being in the process of closing. Later, the Cullen Report (Cullen, 1991) supported the continuation of learning disability nursing as a distinct part of the nursing register and placed emphasis on an aspect of the nurse's role that would refocus on health.

Almost 30 years after the Jay report, in 2001 the Government produced its White Paper Valuing People First (Department of Health, 2001). Although there is little mention of specific services, the notion of inclusion and the use of generic services are clear and forms part of the paper's guiding principles of 'Rights Independence, Choice and Inclusion'. However, this long-awaited policy document, specifically aimed at learning disability, paid little attention to learning disability nursing. Greig (2015) suggests that the policy intention was towards social change, rather than a change in health and social care practices, in that Valuing People represents a 'fundamental paradigm shift' in focusing on changing societal attitudes towards people with learning disabilities as he states that: 'It changed the context of national English policy from being about how services cared for people with an intellectual disability to one of how services supported people to live a full life as equal citizens'. (P.64).

These changes in public policy and societal attitudes since the Jay report in 1979 have been the backdrop for the working lives of learning disability nurses over this period. As the only White Paper published specifically focusing on service for people with learning disabilities since the Jay Report, Valuing People is important in relation to my research study as it forms a key part of the legislative and policy history around the services in which these nurses worked.

In a historical context, learning disability nursing has a different narrative to that of 'general' nursing, and, whilst there is a large body of historical research around nursing, Sweeney and Mitchell (2009) suggest that the history of learning disability nursing 'remains largely invisible'. For a number of years since the Briggs and Jay reports, the identity of the learning disability nurse has been under scrutiny with questions as to whether it even fits into the family of nursing. Inclusion in society is now the key aim in care for people with learning disabilities and there is a wide range of service provider agencies; thus leaving some doubt over the future role of the learning disability nurse. The impact of this debate is not only upon service provision, but also on the future education of learning disability nurses.

This challenge to the status and value of the learning disability nurse arguably predated the 1919 Nurses Registration Act and continued through to the Jay report in 1979. Mitchell (2000) argues that, although the 1913 Mental Deficiency Act gave clarity to the differences between mental health and learning disability, the position of the learning disability nurse has been debated as far back as 1895. In his extensive work examining the position of learning disability nursing from the early 20<sup>th</sup> century through to the 1970s, Mitchell highlights how such debates constitute a precursor for many of the attitudes and beliefs around the role and purpose of the learning disability nurse, many of which still continue today (2001; 2002a and b; 2003; 2004a and b).

In the 30 years that this study has covered, the role of the learning disability nurse has changed dramatically. It is acknowledged that, for some time, learning disability nurses have been working in a range of diverse environments, with potential NHS career opportunities in the early 1980s focused on either hospital-based care or on community nursing teams. However, specialist roles within the NHS do still exist,

particularly in health facilitation inpatient services and other specialist roles (DH, 2007; UK Chief Nursing Officers, 2012; Gates & Mafuba 2015). Much of the literature examining this period has focused on roles and the development of new positions, such as nurse specialists, the acute liaison nurse and nurse consultants, whilst less work exists considering roles outside the NHS (Birchenall et al, 1993; Mason & Phipps 2010; Brown et al., 2012; Moulster et al, 2012). In addition, Mafuba & Gates (2013) have discussed the public health role of the learning disability nurse, suggesting that there has been role ambiguity around this aspect of a learning disability nurse's work: 'The contribution of community learning disability nurses in meeting the public health needs of people with learning disabilities has evolved differently across the UK, resulting in conflicting understanding of this role' (Mafuba & Gates 2013, p.43).

Developments in policy and service delivery models have also changed the locations in which people with learning disabilities require support. The long-stay hospital is no longer the main provider of health services for people with learning disabilities as a more mixed economy of health and social care providers, including the private and voluntary sectors, have taken over. While a range of studies have documented nurses' roles and service change, none has focused on the narrative of these nurses as a collective in order to try to understand the impact of these changes upon identity. However, whilst there is a dearth of literature on the identity of the learning disability nurse specifically, there has been a great deal of commentary about the future of learning disability nursing (Mitchell, 2004; RCN, 2007; DH, 2001; 2007; Gates, 2007; 2010; UK Chief Nursing Officers, 2012; Jukes, 2014; Gates et al., 2015). Such work has emphasised the place of learning disability nursing within nursing more broadly, reinforcing the nursing role, and Gates has examined the impact of a reduction in the number of learning disability nurses. (Gates, 2007; 2010).

More recent publications post data collection have also discussed the future role of the learning disability nurse and provided a framework for research, leadership and management (UK Chief Nursing Officers, 2012; Jukes, 2013; Gates et al., 2015). Further to this, the UK Chief Nursing Officers also produced a report aiming to provide direction for the profession. Building from the *UK Modernising Learning*

*Disabilities Nursing Review: Strengthening the Commitment* (2012) highlighted four key areas of development around this area of nursing; 'strengthening capacity', 'strengthening capability,' 'strengthening quality' and 'strengthening the profession'. The report acts as a backdrop to contemporary learning disability nursing, clarifying the Department of Health position, whilst also acknowledging a decrease in the numbers of learning disability nurses and the difficulty in locating those who work outside the NHS. This report was published after the collection of the empirical data for this study, but, like previous reports (DH, 2001; DH, 2007), it may serve to reinforce the perceived role of the learning disability nurse from within the profession.

The literature reviewed thus far illustrates change, but also highlights uncertainty and doubt over the future of learning disability nursing. This, in turn, raises questions around why people choose to pursue a career in which their identity is often scrutinised and the value of their role challenged. Where nursing has historically been seen as ministering to or caring for the sick, learning disability nursing has its historical basis in the removal from society and containment of people with learning disabilities. The places where learning disability nurses were employed may be seen as a reflection of societal attitudes towards the care of people with learning disabilities at specific points in time, but they were also part of shaping the identity of learning disability nurses today and where they see themselves in the 'family' of nursing. Within my study, this is important as it forms a key part of understanding the context of the narratives of the participants.

In mapping the literature around the place of people with a learning disability in society and the history of learning disability nursing, the focus has been on the developing role of the nurse (Mitchell, 2002; Stewart and Todd, 2001), the practices within service settings such as institutions (Potts and Fido, 1991; Wright and Digby, 1996; Atkinson et al., 1997;) and policy change (Malin, Race & Burton, 2004; Malin & Race, 2010; 2011). Whilst very few studies have focused on the narratives of learning disability nurses, the studies suggest a collective identity and a historical timeline important to my study as a 'backdrop' to the narratives of the 20 learning disability nurses who took part.

As has been established, the development of learning disability nursing is inherently situated within a historical context shaped by societal attitudes, policy change and institutional practices. Mitchell's extensive work also reveals that the scrutiny of the history of learning disability nursing reveals an earlier questioning of the place of learning disability nursing within the family of nursing; 'learning disability nursing has been under constant question from the 1920s until the 1970s when the Briggs Report suggested that a new profession should emerge and, as a result, the Jay Committee was set up' (Mitchell, 2002, p.19).

This part of the literature has also revealed a changing service provision for people with learning disabilities as large NHS hospital provision closed and more services were provided in communities, bringing with it a further challenge to learning disability nursing and its place within non-NHS services. In order to further understand learning disability nurses and nursing it is important to first examine literature around why people choose nursing, and more specifically learning disability nursing, as a career.

## **2.3 The education and training of nurses**

Alongside the changes in service provision for people with learning disabilities over the past 30 years, there have been many changes in the education of nurses. In the context of my study it is important to acknowledge these changes as it is proposed that they have had an impact on the underpinning philosophies of care, service models and the ways in which nurses see their role and identity.

Prior to the early 1980s an apprenticeship model existed, with nursing students employed in a health authority and undertaking their education from their employment base in what was usually a school of nursing and midwifery run by and attached to the hospital (Bradshaw 2000). McClimens and Nutting (2014) suggest that the forming of the United Kingdom Central Council for Nursing, Midwifery and Health Visiting (UKCC) in 1983 was a '*significant change*' as its '*major initiative was to initiate curriculum reform*' (p.18). A key to reform in nurse education came in the form of what was known as Project 2000, a three-year programme situated in higher



education establishments. An innovative aspect of the programme is summed up by McClimens and Nutting as:

The common foundation programme (CFP). Taking up the first half of the three-year qualification period, the CFP was designed to equip all students with basic knowledge and skills through exposure to service users from a variety of diagnostic and clinical backgrounds. (2014, p.18 )

However, there were concerns that this approach would mean the smaller branches (those other than adult or general nursing) would lose their identity and be swamped, often on sheer numbers alone, by the adult specialty nurses. There were also criticisms at the time that the move of nurse education into the higher educator sector and universities would mean a focus on academic achievement to the detriment of vocational competence. What followed the 2010 standards for nursing, midwifery and health visiting from the NMC was a move towards an all-degree education for nurses and midwives across the UK.

It appears that the move from a hospital-based certificate-level qualification for nurses to undergraduate and post-graduate courses based in HEIs has been a challenge for some who do not view nurses as equal to other health professions, such as physiotherapists, occupational therapists, or biomedical scientists. There are numerous debates around this, but the relevance for this study is linked to education in the field of learning disability nursing within these changes more generally to nurse education, its philosophy and location.

## **2.4. Choosing nursing as a career**

The literature reviewed around the history and current position of learning disability nursing suggests a continuous challenge to its existence as a field of nursing, however, whilst the numbers of learning disability nurse student commissioned places have reduced across the UK (Gates 2011), there remain opportunities for individuals to choose a career path in learning disability nursing; to undertake pre-registration nurse education in one of the Higher Education Institutions (HEI) in the UK and to then register as a nurse with the Nursing & Midwifery Council (NMC) on successful completion of their programme.

These programmes, in common with all fields of nursing, are commissioned by what at the time of the data collection were the Strategic Health Authorities (now Health Education, England) in England and similar bodies in the other three countries of the UK. Whilst commissions have been reduced across the UK in learning disability nursing, data suggests that almost all higher education institutions (HEIs) recruited below their commissioning targets in the years 2009-2010 (Gates, 2011). This, in turn, led to attention being drawn again to the nature of learning disability nursing and its attractiveness as a career option. In order to consider recruitment into learning disability nursing it is first pertinent to take a wider and more general view of nursing. There is limited literature around choices to become a learning disability nurse, whilst a broader literature exists around nursing overall.

The motivating factors for choosing nursing as a career have been the subject of international research for more than a decade. Studies around recruitment into nursing tend to focus on those participants at school, due to leave school, or recently recruited to nurse education. Furthermore, the focus of these studies often centres on gender differences (Zyberg and Berry, 2005), personality influencing choices (Eley et al., 2012), perceptions of nursing as an attractive career (Hemsley-Brown and Foskett, 1999), and the influence of others (Price, 2009). In particular, Neilson and Jones assert that, since the 1980s, there has been *'fewer school leavers pursuing nursing as a career option'* (2012, p.591). In their study in Scotland they focus on the career choices of more than 1,000 (n=1059) 5<sup>th</sup> and 6<sup>th</sup> year high school students aged 16, 17 and 18, finding that almost 72% of the students would not choose nursing as a career. Additionally, where higher grades were predicted, the likelihood of choosing nursing as a career was reduced further. This is also supported by early studies that suggest nursing is not the first choice of career for many, with Rognstad (2002) finding that 45% of students had wanted to study other subjects. Mooney et al. (2008), studying 23 nursing students in Ireland, also suggested that nursing is often not a first choice of career. More than a third of students in their study had been interested in pursuing other careers had they achieved higher grades, highlighting other options such as teaching, physiotherapy, medicine and radiography. The influence of others also appears to be a factor in choosing careers, including nursing. Families, careers advisers, teachers, friends and other nurses have all been identified as having an influence on those who chose

nursing as a career: 'the main factors that influenced entry to the profession were related to the knowledge of nursing through family members and exposure to work experience' (Mooney et al., 2008, p.389).

These influences were also picked up in other studies (Neilson et al., 2012; Beck, 2000; Price, 2009; Williams et al., 1997; Larsen et al., 2003). Gender also has an impact on career choice and perception of particular careers. Nursing has been viewed as a female occupation for many years and this is still evident in the findings of a number of the studies highlighted here. In a study by Whitehead et al (2007), all respondents who showed an interest in nursing were female and male respondents suggested that they were not interested because it was 'a girl's job' (Whitehead et al., 2007 p. 495). In a larger-scale study (Neilson and Jones, 2012) of more than 1,000 respondents, female students were 3.77 times more likely to consider nursing as a career choice. They go on to argue that: 'Nursing is the most extremely feminised of careers, as a consequence most males who represent a vast prospective number of recruits are virtually prohibited' (Neilson & Jones 2012, p.591). This suggests that the social construct of nursing around femininity and the notion of 'care' as a female activity is a barrier to male participation. In the study by Mooney et al in Ireland, a male participant states: '*I was influenced by the whole social thing of being a guy and it wasn't a positive influence*' (Neilson & Jones, 2008, p.592). They go on to suggest that the male nurses in their group made up a significant minority and 'There was general agreement among the males and females in the group that society in general does not identify positively with males entering the nursing profession' (2008, p.389). The men studied by Mooney et al all highlighted positive encouragement in their careers from families. Beyond gender, it appears that the influence of others is also a key factor in decision-making.

However, a number of studies identify negative views of nursing from young people, with many viewing nursing as a low-paid job with few career prospects (Whitehead et al., 2007), and of less importance in comparison to medical training (Neilson and Lauder, 2008). Hemsley-Brown and Foskett (1999), in their study of the perceptions of young people of careers such as engineering and nursing, concluded that 'although young people expressed their admiration for the work of nurses, this was rarely matched by envy, or a desire to become a nurse themselves' (p.1349). Further

to this, the values attached to nursing, such as care and compassion, may be outweighed by an individualistic focus on, for example, financial reward. Low pay and low status have been acknowledged as factors inhibiting interest amongst young people towards a career in nursing (Whitehead et al., 2007).

A number of studies have focused on perceived aspects of personality that have led research participants to choose nursing. Altruism, or the desire to help or to care for others, has been an unsurprising finding of a number of studies where motivations to choose nursing as a career have been examined (Hemsley-Brown and Foskett, 1999; Beck, 2000; Whitehead et al., 2007). In the study by Whitehead et al (2007), 106 high school students across three schools responded to a survey around career choices. Of the 106 respondents, 21% (all female) said they would consider nursing as a career. Around 56% of respondents felt that 'caring for people' and 'making them well' were key elements of what nurses do. This theme around altruism is also identified by Hemsley-Brown and Foskett, who found that 'the main reason given for wanting to become a nurse, by the majority of young people, was the wish to be involved with 'helping people' (1999, p.1347). However, the study findings also suggest that participants associated nursing with self-sacrifice and saw the work that nurses did as manual, low skilled and 'dirty'. Significantly, but not surprisingly, nurses' work was seen to be confined to a hospital setting, a view also supported within a number of other studies. As such, this narrow view of nursing and where nurses work associates nursing with a medical model of care located within hospital settings and does not reflect the diversity of settings in which nurses practice. This is interesting for my study as it suggests that, when young people are considering a career in nursing, they are focused on those roles within hospitals and are not considering the breadth of nursing roles in other settings, and therefore potentially not considering the role of the learning disability nurse. It is also suggested that career decisions are further influenced by self-concept (Anderson, 1993), and therefore those who see themselves as caring people may be motivated towards a career in nursing or a similar role such as teaching (Hemsley Brown and Foskett 1999; Mooney et al, 2008).

Overall, studies suggest that students are more likely to choose nursing as a career if female, have poorer exam performance than they would have liked, have a positive

attitude to nursing, and have careers advice supportive of their desire to nurse. Perception of the nurse's role, prospects and position within health care appear to also play a large part in relation to the respondents' views within these studies and, while not specific to learning disability, there are some key issues here around how young people perceive nursing; mainly 'general nursing'. As Hallam states, 'the public image of a profession is an important barometer of the group's status in society' (2002, p.35). Perception of specific job roles is often influenced by the media (Jinks & Bradley 2003) and, while media images exist of nurses working in a range of 'general nursing' settings (often hospital based), fewer images exist of learning disability nurses (Owen and Standen, 2007). In addition, the past three decades have seen the locality of care for large numbers of people with learning disabilities in England move from institutionally-based locations to private provision.

In one of a limited number of qualitative studies into why people choose learning disability nursing in particular, Owen and Standen found that 'three key themes had emerged from the analysis, namely, previous experience of people with learning disabilities; reasons for choosing the learning disability branch of nursing; and doubts, uncertainty and concerns' (2007, p.263). Fifteen of the 19 learning disability student nurses in the sample had previous experience of working with people with learning disabilities in a variety of settings, of which five participants identified this experience as shaping their decision to pursue learning disability nursing as a career. As Owen and Standen state: 'embarking on their learning disability nurse training was a natural progression from the work they had previously been doing as paid care staff' (2007, p.264). Importantly, this research highlights how respondents also noted that it was the opportunity to work in community settings rather than hospital settings that attracted them to learning disability nursing. Although it is not clear whether the respondents were aware of this from their previous work experience, they do specifically mention the community setting as a motivator for choosing this field of nursing.

As with the research into more generalised nursing discussed previously, altruism is identified as another important factor in choosing learning disability nursing as a career. Around a third of the participants in Owen and Standen's work talked about 'caring for', 'understanding' and 'helping those less fortunate' (2007, p.267).

Interestingly, respondents also connected what they perceived to be the learning disability nurse's role with their own 'personal strengths and personalities', suggesting that they saw this role as part of their identity: 'I always seem to take on the role of helping... it just seems natural for me to be in that kind of role' (2007, p.264). They also suggest that there is an attraction to the working environment and 'the nature of the work', stating: 'wanting to help people, watching how they progress on a day-to-day basis, being with the client over a long period of time, and building up positive relationships, were frequently expressed as benefits of working as a learning disability nurse' (2007, p.264). Additionally in Owen & Standen's study, 'nine of the students described a range of personal life events that prompted their decision to work in this field' (2007, p.264). These descriptions of life events and their impact on choice of career suggest that these decisions are often complex and take into account an individual's changing circumstances. This is an important consideration within my own study as I am interested in the changing circumstances of an individual and how this is narrated as a potential impact on their working lives. These changing circumstances are also impacted upon by age and life experience, and the 19 participants in Owen and Standen's study had a mean age for women of 32 and for men 34. As Owen and Standen focused on students six months into their course who had already chosen learning disability nursing as their career pathway, we might expect to see some of these findings as they potentially legitimate their career choice. I could expect to see something similar in my study as I am focusing on those who have chosen a career in learning disability nursing rather than those who did not.

The findings of such studies into the motivations for entering the field of learning disability nursing are also echoed in the wider literature on recruitment into mental health nursing, including Barriball and White (1996), who identified that mental health students often made their career choices later in life, while studies by Robinson et al (1999), Pye and Whyte (1996), Hardyman and Robinson (2001) suggest a diversity amongst the mental health student nurse population with more men, older students, and a greater range of relevant work experience. Whilst there is limited literature specifically focused on the recruitment of learning disability nurses, it may be suggested that recruitment to learning disability nurse training and the motivations for choosing this field of nursing may have more similarities with mental health

nursing than with the adult or pediatric fields of practice. It is not, however, within the remit of this work to undertake a full comparative review of the literature, but to highlight key studies in this area and their relevance to the present study.

As smaller numbers of learning disability nurses are commissioned each year (Gates, 2010), it is important that we understand the motivations and influences of those who choose learning disability nursing. Many roles now exist outside the NHS and, whilst those who have already started their journey in learning disability nursing may be aware of the context of learning disability nursing and the diversity of potential roles, those who are thinking about this field as a career option may have stereotypical views of nursing and healthcare. Many student nurse recruitment campaigns focus on adult nursing (Wells et al, 2000) and this in itself can perpetuate a societal view around the roles of nurses and lead to a focus on hospital-based 'technical' nursing (Owen and Standen, 2007). As such, it is of importance that we understand why people are motivated to become learning disability nurses and acknowledge that this is fluid, changing, and shaped by societal attitudes, services and self-concept.

## **2.5 Being a learning disability nurse: Role Identity**

This section examines the literature related to identity, role diversity and relationships with others. Imbedded within this are references to change as my study focuses on a thirty year period which, as the literature demonstrates has included many changes in service provision and the role of the nurse.

### **2.5.1 Role Diversity**

There have been radical changes in the working lives of learning disability nurses over the past 30 years. This has largely been shaped by the move from being a predominantly hospital-based profession (Sweeney and Mitchell, 2009), to one in which nurses work within a diverse range of environments in response to the changing needs of people with learning disabilities (DH, 2007; DH, 2001; UK Chief Nursing Officers, 2012; Gates, 2011). This is reflected in the literature through a number of studies that focus on specific roles held by learning disability nurses, and often in response to key changes in government policy. An example is the work of

Pointu et al (2009), describing the role of the Acute Liaison Nurse, which they identify as being able to respond to many of the difficulties faced by people with learning disabilities attempting to access acute hospital services. A previous study by Gibbs et al (2008) utilises focus groups to identify the benefits of this 'new role' of Acute Liaison Nurse in supporting people with learning disabilities. Both of these studies have clearly linked government guidance with outcome measurements following the introduction of these new roles for learning disability nurses in acute hospitals. Building on a previous study by Bollard and Jukes (1999), Jukes (2002) suggests a health facilitation role for the specialist learning disability practitioner, highlighting the aspects of the learning disability community nurse's position that could be incorporated into the development of this new role, suggesting that: 'The role demands an integral adoption of selected models of change and leadership' (p.698). Jukes, like many others, has proposed a range of roles for learning disability nurses over the past three decades as the nurse's role within the long-stay hospital disappears and their role within community settings changes.

As the role of the learning disability nurse changes over time, in line with both policy and service models, there has been no shortages of suggestions as to where and how learning disability nurses can perform their role; potentially adding to the lack of clear professional identity and direction.

### **2.5.2 Relationships as part of the nurse's role**

Nursing as an activity includes the building and maintaining of relationships; not only with those in the nurse's care but also with fellow nurses, other professionals, and families and carers. The importance of relationships between learning disability nurses and people with learning disabilities has been acknowledged in a number of studies, including those focusing on power relationships (Ryan and Thomas, 1987; Oswin, 1973; Potts and Fido, 1991; Mitchell, 1998). The relationships between staff and patients described in these studies were often based on unequal power, reflecting the dominant views held within society at the time that people with learning disabilities needed more control than 'care'. Potts and Fido document an account, in which a participant discusses life in an institution, stating:



She was a twister! She twisted the money, fiddled it. They used to kick the patients about. Kick 'em; give 'em stick'n that, bang 'em about! It was what the staff did. I were only 13 then. There were some that were alright but there were some bad buggers in there, knocked the patients about! (1991, p.109)

Such abusive relationships are prevalent throughout these recorded accounts of 'institutional living', with the literature in this area often emphasising the unequal power balance between nurses and people with learning disabilities. When viewing this through a historical lens, as we move towards the present day, we see the changing nature of relationships reflected in the way in which the person with a learning disability is presented. Contemporary learning disability nursing exists in a landscape of espoused philosophies of empowerment, community integration. Whilst scandals such as 'Winterbourne' (Northway & Jenkins, 2012; Parish, 2014) exist and remind us that the power base still requires challenge in some areas of practice, studies that have focused on the role of the nurse in relation to advocacy and empowerment suggest that a shift in the power base and the changing nature of relationships between learning disability nurses and those they care for (Northway et al, 1997). Policy that introduces initiatives such as personal budgets, introduced following The 1996 Community Care (Direct Payments) Act, and Person Centred Planning may be seen to have the potential to positively influence relationships, but a number of studies highlight power imbalances when attempting to administrate these. Beadle-Brown (2005) states:

There is a shared aim of both PCP and direct payments to enable people (including those with learning disabilities) to have as much choice and control as possible over their lives and the services and support they receive. There are examples available in the popular literature about how both direct payments and PCP can have beneficial effects. (p. 172)

However, using a social work perspective, Concannon (2006) suggests that:

This new revolution is not without its problems for people with learning disabilities, arising primarily because of the responsibility placed on the client as employer and administrator. How direct payments are administered by people with additional cognitive and communication difficulties is an added problem. Although Valuing People speaks at length about direct payments, as with past policies, it fails to produce an argument about how this can be successfully achieved in practice. Service users will be responsible for administering budgets running into thousands of pounds of public money each

year, and insufficient support will leave many vulnerable, distressed and open to exploitation. (p.34)

Whilst this perspective from social work highlights some of the difficulties suggested in implementing policies which could offer a greater power balance to people with learning disabilities, the history of learning disability nursing provides a lens through which to view the underpinning philosophies of care and the role and function of nurses within this. The early history of custodial care based on eugenic beliefs about the nature of learning disability is described in the literature around institutionalisation (Potts & Fido, 1991; Oswin, 1973; Ryan and Thomas, 1980), but, as policy focused on community-based care for people with learning disabilities, the literature focused on the role of the nurse in relation to people with learning disabilities, changing its focus to represent a more human rights-based approach with a social model appearing to underpin many of the discussions. In addition, there has also been a growth in research that involves people with learning disabilities as active participants. Furthermore, the inclusion of people with learning disabilities as researchers themselves, rather than just a part of the research process, changes the nature of 'evidence', adding a service user lens of scrutiny to the role of the learning disability nurse (Northway, 1997). Often, these studies describe the person's experience of accessing services and these experiences may also include the services provided by nurses. This reflects a potential change in the balance of power between those who organise and deliver services for people with learning disabilities and those who use those services. Philosophies of person centred care and service user involvement have underpinned many of the approaches to the care of people with learning disabilities from the inception of community care.

The NHS Plan in 2000 (Department of Health 2000) had, at its heart, carer and service user involvement in the design and delivery of services, and the development of a wide range of advocacy services (Race, 2007) for people with learning disabilities have been a key part of this involvement, which is often challenging when applied to those service users who have learning disabilities (Hoole & Morgan, 2011). In Hoole & Morgan's study, which utilised focus groups to examine the views of service users of being involved in decision making, there was a desire to be involved in decision making, however, the researchers state: 'Participants told us of

the difficulties they experience, their current and experiences of inclusion and power within services and their visions for future possibilities' (p.39). It was not clear within this study whether the comments from services users about staff related to nurses, but it does demonstrate that, whilst service user involvement is a clear policy direction, the practicalities of this happening in a meaningful way for people with learning disabilities is more challenging.

This movement towards engagement with people with learning disabilities as users of our services has not only impacted academic research but also how services are evaluated in practice. Whilst the nature of learning disability nursing has changed over the past three decades, recent policy reinforces the place of 'values' within the field. *Valuing People: A new strategy for learning disability in the 21<sup>st</sup> Century – A White Paper* (DH 2001) and the follow up report, *Valuing People Now* (DH 2009), identifies core principles of Rights, Inclusion Choices and independence. This is further articulated in *Strengthening the Commitment*, which states that: 'Learning disabilities nursing is based on clear values that include placing individuals at the centre of care and ensuring they are fully involved in all aspects of planning and intervention.' (UK Chief Nursing Officers, 2012, p.8). This policy direction, it could be argued, sets the tone for a new type of relationship between those who use services and those who manage and deliver those services, including learning disability nurses, although studies such as those by Hoole & Morgan (2011) may suggest this is not reflected in how many people with learning disabilities feel about their role in decision making.

## **2.6 Identity and role theory**

A key aim of this work has been to understand the working lives of learning disability nurses and their professional identity. However, in order to provide context and explore the professional identity of learning disability nurses, it is important to first examine theories around identity. The literature relating specifically to nursing tends to focus on professional identity and the public image of nurses, particularly in regard to the acquisition of professional identity through socialisation and the identity of specialist nurses (Crawford et al, 2008). A more recent analysis of nursing identity literature between 2008 and 2013, undertaken by Bell et al (2015), supports the view

that, whilst a majority of the work examined focuses on professional identity, much of it 'lacks methods and data to support its hypotheses'.

In its broader context and originating in the psychological and sociological traditions, social science enquiry has had a prominent focus on identity for decades. Nurses exist not only as individuals with a self-identity but also as a collective – the profession of nursing, and specifically learning disability nursing. In addition to the broader theoretical constructs around identity more specifically, theories of relational and social identity were examined when undertaking this critical review of the literature in order to establish a theoretical framework.

### **2.6.1 Social Identity Theory**

Nursing takes place within a social context and is bound by the culture and norms of the society in which the activity of nursing takes place. This study has a focus on both the individual identity, how the participants see themselves as a learning disability nurse, and also the collective identity of learning disability nurses and the impact of being part of a group of nurses.

Much of the identity literature in nursing is linked specifically to the understanding of professional identity, few theorists focused on pure social identity theory in relation to nursing. However, a small number used social identity theories to discuss broader elements of nursing identity. Oaker and Brown, who in 1986 studied the views of nurses in a hospital setting, suggest that inter-group behaviour is an indicator of identity in regard to how the nurses saw themselves in relation to others from different nursing specialisms. Their study draws on theories of identity espoused. Tajfel, (1978; 1986), and a number of other scholars who developed social identity theories in the early 1970s to explain group processes of self-categorisation and social categorisation (1971), were linked into this to provide a lens through which to view the place of an individual within a group, and also the inter-relationships between those groups (Tajfel & Turner, 1986). The place of the individual within a group and group belongingness are key tenants of the work of Tajfel as he explores in-group behaviour and relational identity within this. This work around the individual within a group is a key element of understanding the learning disability nurse, not only in the context of the group of learning disability nurses but also of other nurses.

This theoretical underpinning of social identity theory and group behaviour has underpinned my study.

Further to this, Millward (1995) uses a framework of social identity theory in order to explore nurses' identity and intergroup identity. The nurses within her study either identified within the 'traditional' stereotype of nursing, with its identifiers such as care and 'service to others', or as a professionalised group comparable with medicine. The distinction made was particularly between more experienced nurses, who described themselves as 'professionally distinctive', in contrast with the more junior nurses, who used the traditional stereotypes and descriptors of nursing around gender and the 'care to cure' philosophy to describe their identity, which Millward suggests constrained 'identity possibilities' (p.321). Millward's study in 1995 also acknowledged that the nature of nursing identity was changing as the 'newer' nurses in the study related to an identity, which was a 'new more instrumental representation', which Millward argues 'challenges pre-existing images of nurses in low status role by claiming that their qualities, skills and abilities are complementary rather than subordinate to medics' (p.318) whilst highlighting that 'changes in identity are thus being forged' (p.321).

The study by Millward preceded some major changes in nurse education as training moved into the higher education sector and the academicalisation of nurse education began. The findings suggest, however, that nursing identity had begun to change even when the public image had not. This remains an important finding for my study, as the findings of Millward's study suggest these changes in the way in which nurses perceive their identity are shaped by public perception of the identity of the nurse.

In a later study, Burford explores the relevance of social identity theory to medical education, suggesting it provides a 'powerful framework' in which to view some of the challenges within medical education (2012, p.144). In his work he suggests that 'social identity emerges from an active process of categorisation, operating on socially meaningful stimuli' (2012, p.144). Self-categorisation corresponds directly to group behaviours as in-group and out-group behaviours, and the subsequent alliance with the group must be viewed as positive in order to maintain motivation to be part of the group. He also notes the comparative nature of categorisation as each group is measured against the other as we identify who we are through also

establishing who it is we are not. This is in consonance with theories of social identity, including the work of Jenkins who suggests that identity is predominantly shaped by society and the groups in which we live, defining it as a '*multi-dimensional classification or mapping of the human world and our places in it, as individuals and as members of collectives*' (1996, p.5). This definition suggests that, when we examine the identity of nurses, we do so not only as individuals, but also as a group. Jenkins also goes on to highlight the active role others inherently play in social identity: 'Others don't just perceive our identity, they actively constitute it. And they do so not only in terms of naming or categorising, but in terms of how they respond to or treat us' (1996, p.96). Whilst Jenkins may provide us with an introductory level understanding of social identity theories, he offers the underpinnings for a wider view of the meaning of identity in a social context. This link between collective identity and social identity theory espoused by Tajfel and Turner (1986), Jenkins (1996) and others is of particular interest in the context of the present study as it places the individual within the context of a group and, for this study, that group is learning disability nurses.

In a study in 2012 by Machin et al, the professional identity of health visitors was explored, finding that the history of health visiting had affected role identity. The study also suggested the '*instability in health care systems (which) may create identity uncertainty*' (p.1527). Machin et al drew on the work of Castells (1997) around collective resistance identity, whereby policy and guidance is 'ignored' as a form of resistance to change (Castells, 1997). In order to maintain 'identity equilibrium' (p.1533), Machin et al also propose their findings suggest the:

Macro level policies can directly affect the identity equilibrium of individuals, for example health visiting role, title change **or** indirectly through policy drivers, organisational change management positions in the health care system. (p.1533)

Whilst this literature was reviewed post data collection, and is a small-scale study (17 participants) which focused on health visitors rather than learning disability nurses, there are many similarities in the changes health visiting as a profession have faced, and for the purposes of my study it has informed the discussion and is highly relevant.

A number of studies have focused on the application of social identity theory in an organisational context (Sluss & Ashforth, 2007; Ashforth & Mael, 1989; Currie et al, 2010) and, whilst these studies sit outside of nursing and health care contexts, they provide an understanding of identity theory from an organisational perspective. Ashforth and Mael (1989) argue that social identification is linked to group identification and then both group and individual behaviours then stem from what is acceptable within that group context. They apply the concepts of organisational behaviour and suggest that *'individuals have multiple identities and inherent conflicts between their demands'* (p.35). The connection here between group identity, social identity theory and organisational behaviour has relevance to my study of learning disability nurses who are part of a wider group of learning disability nurses but also organisations and systems such as the NHS. Understanding the participants' perception of themselves, as a learning disability nurse in the context of their organisation, will be crucial to understanding perceptions of their identity.

### **2.6.2 Similarity and Difference: The role of the 'other'**

Using a framework of social identity creates an opportunity to explore the concept of 'othering' and examine the place of learning disability nurses within the wider family of nursing. Much of the social identity and relational identity theories focus on the 'other' as a key construct in understanding who we are in relation to others as both individuals and groups. Jetton et al argue that 'intergroup distinctiveness', which they define as

The perceived difference or dissimilarity between one's own group and another group on a relevant dimension of comparison' is 'central to intergroup theories such as social identity and closely related to self-categorisation theories (2001, p.621)

In their study they suggest that those who are 'high identifiers will defend group identity when group distinctiveness is highest' (p.637). This particular aspect of identity theory is one which is highly relevant to the study, as much of the history of learning disability nursing and discussions about its future have been located in the debate around the status of learning disability nurses and who they are in relation to other nurses and professional groups. The literature around group distinctiveness

and 'othering' in relation to identity theories suggests that the more distinctive groups are, the more likely members are to compare themselves to others.

### **2.6.3 Relational identity**

Ashforth and Sluss (2007) provide a theoretical stance on relational identity and identification in organisations that suggests that our sense of self 'is influenced by interpersonal relationships and the consequent interplay of three levels of identity: individual (or personal), interpersonal, and collective (or group, social)' (2007, p.9). They go on to argue that relational identity links directly with role relationships and role identification, or what they describe as 'the extent to which one defines oneself in terms of a given role relationship' (2007, p.11). The model of relational identity proposed by Sluss and Ashforth encompasses the three aspects of identity articulated by earlier theorists Brewer and Gardner: 'the individual, the interpersonal and collective' (1996, p.10). They suggest that all of these aspects of self become the relational identity, interacting in such a way that it is this complex combination of these aspects of identity which ascribe meaning to identity through role. In the context of both social identity and relational identity theories, the place of the individual in relation to others is key. Relational identity as espoused by Sluss and Ashforth (2007) provides the theoretical framework for exploring the role of the individual in relation to others, both inside and outside of the profession of nursing. This is significant in the context of the present study in relation to examining the working lives of learning disability nurses and their professional identity in regard to not only how they understand their role based on their individual identity, but also in relation to others. Further to this, Ashforth and Mael (1989) identify that positive differentiation occurs more frequently when a group feels threatened or their resource base is challenged (1989, p.35). The consistent challenges to their status as a profession suggest that this may have had a substantial impact on the identity of the learning disability nurse, raising the question of whether the participants of this study will demonstrate positive differentiation within their own identity narratives.

Willetts and Clarke suggest that social identity theory can be used as a framework for exploring the professional identity of the nurse. When commenting on the literature base they suggest that 'little research has been conducted into the development of the professional identity of nurses through the social context of their



nursing work' (2012, p.165). However, many debates over the decades have been based on a perception of what learning disability nurses do in relation to other nurses. These debates are not only from outside of the profession, but also inside as nurses compare themselves to each other, which is an expected response to relational identity. The present study uses identity theories as a framework to explore identity of the learning disability nurse, not only through their descriptions of self within their own narratives, but also through how they describe others as seeing them and how they see others. It is the descriptions of interactions which will provide a lens to view not only how learning disability nurses see themselves but also how they perceive how others see them: their identity.

#### **2.6.4 Identity and the changing role of the learning disability nurse**

Conway suggests role theory is 'a collection of concepts and a variety of hypothetical formulations that predict how actors will perform in a given role, or under what circumstances certain behaviours can be expected' (1988, p.63). This relates to social identity theory as a theoretical framework within my research study in that the 'performance' of these roles takes place within a group dynamic, whether that group is learning disability nursing or nursing per se. It is also relevant in that the role of learning disability nurses has been changing and evolving over the past three decades and the study interviews are intended to encourage participants to narrate these changes.

Brookes et al define 'role' as a 'description of the behaviours, characteristics, norms and values of a person or position' (2007, p.147). In their work they examine change within the community nurse's role in regard to notions of role ambiguity, role conflict, role overload, role identity and role insufficiency. Of these, role ambiguity is particularly useful in the context of this study, as a number of commentators suggest that this is a key feature of the learning disability nurse's history. As has previously been established, questions around the status of the learning disability nurse and their role have been debated for a number of years. From the growth of the CNLD in the 1970s (Barr, 2006), policies of social inclusion have enabled the growth of roles for learning disability nurses in areas such as health facilitation (Foster, 2005) and acute liaison (Brown, 2012) to develop and flourish alongside specialist nursing roles in challenging behaviour, mental health, epilepsy, and more. However, whilst a

number of roles grew and flourished those within and outside, the profession did not always understand them. Ross (2001) and Fyson (2002) suggest that a lack of role clarity can also impede policy development. However, we may also need to consider that a lack of policy development may also impede role clarity.

This focus on role theory in relation to symbolic interactionism, as opposed to structural functionalism, will provide a framework from within which to analyse the nurse's perceptions of these roles, rather than the organisation's reason for the creation of them. As Sluss and Ashworth state:

Structural functionalism emphasises how roles are created to fulfil institutional needs, whereas symbolic interactionism emphasises the agency of individuals in socially (re) constructing the meaning and enactment of those roles. (2007, p.12)

The theoretical framework of symbolic interactionism in relation to role theory offers an opportunity to examine the interactions between people towards a goal or an outcome, examining the role of learning disability nurses described through their narratives in a wide range of settings. This framework can also be a useful tool for exploring change and reactions to change within roles: 'as professional groups navigate the processes of change there is often a need to explore, refine and often redefine roles' (Brookes et al, 2007, p.148). Within this context, identity is not static concept that can be built or constructed, but a notion that is fluid and constantly changing (Baumann, 1996; Yuval-Davis, 2011). As Baumann states, identity offers 'an escape from uncertainty', going on to suggest that, in the ever-changing landscape of modern society: 'the hub of postmodern life strategy is not identity building but the avoidance of fixation' (1996, p.24). However, according to Nelson and Gordon, this avoidance of fixation comes at a cost. They argue that, in its attempt to gain legitimacy and professional status, nursing is in danger of losing its identity as roles constantly change and boundaries with other professional groups become blurred. Maben and Griffiths also identify this challenge within nursing identity, stating that 'in the past the brand of nursing was strong. Nursing was seen to have a clear identity and people knew what a nurse was and what a nurse did... Today the brand appears less strong, nursing is more complex, and varied and multiple images prevail' (2008, p.12).

In relation to this, Secrest, Norwood and Keatley (2003) suggest that, historically, nurses have found it difficult to define nursing and to distinguish it from other health care disciplines. Turkell (2001) also acknowledges the challenge nurses face when attempting to combine the science and art of caring within the economic context of the health care environment. This is relevant to my study, as learning disability nursing has had difficulty in defining a role that has often been seen by those outside of the field to be incongruent with nursing identity and the notions of caring for those who are sick (Mitchell, 2001). Further, the literature around nursing suggests a changing identity - changing within the context of society, social change, and the health policies underpinning nursing care. This changing identity leads to a change in roles. In relation to this, Hurley (2009) suggests that social and health policies are creating multiple roles for mental health nurses, impacting upon identity. In a further study of mental health nurses, Majomi et al suggest that nursing roles are 'continually being redeveloped and re-evaluated' (2003), and, whilst early theorists such as Mead (1934) may have suggested that roles may begin with an initial period of 'socialisation' or 'role taking' followed by a period of 'statis', this suggestion is not necessarily reflected in the changing nature of nursing today. Majomi et al describe the concept of 'punctuated equilibria'; whereby organisational or personal change is brought about change in the stasis of the role. Whilst this study focuses on conflict across home and work roles, and the stress related to this, aspects of the study around role conflict and multiplicity of roles could also resonate for learning disability nursing, as policy change over the past three decades has changed not only the places and spaces in which learning disability nurses work, but also the societal change in attitudes towards the people these nurses care for.

#### **2.6.6 Professional identity and Professional socialisation**

A range of studies exist exploring the professional socialisation of nurses and, while early literature has had a focus on the chronological aspects of that socialisation (Etzioni, 1967; Goffman, 1969), later theorists suggest an approach that is more focused on the interaction of the individual with the values and norms of a group and internalisation of those values and norms (Howkins and Ewens, 1999). In their study, Howkins and Ewens (1999) explore the role perception of students undertaking a specialist community nursing qualification. Whilst not specific to the learning

disability nurse, the study identified one learning disability nurse within the sample. Broader findings provide insights into the development of professional identity in learning disability nursing; professional socialisation did not appear to take place in a linear fashion but was fluid. Socialisation of students into new roles is shaped by unique past experiences and their concept of self; developed during their time on programme. Johnson et al (2012) also identified the importance of education in shaping professional identity through professional socialisation. They suggest that, whilst socialisation is a lifelong process, education and training are 'vital' in shaping professional identity. Although a relatively small-scale qualitative study, as acknowledged by the authors, the key conclusion is still relevant in regard to examining the changing role of the learning disability nurse: 'Professional socialisation should be seen from a new perspective. It can no longer be seen as a reactive and linear process. Nurses at any point in their career development can change the way they view themselves and their role' (Johnson et al 2012, p.563). As an area of nursing that has changed so dramatically, the impact of this change on the professional socialisation and professional identity of the learning disability nurse must be considered. Johnson et al, in their review of the literature around nursing professional identity, also suggest that there are also benefits to patients and co-workers where 'a positive and flexible professional identity exists' (2012, p.562). Whilst the studies specific to professional identity in learning disability are limited, this work identifies a number of studies where the focus on professional identity is transferrable to learning disability nursing. Furthermore, Johnson et al go on to assert that sense of self and professional identity is 'augmented' and that 'it is the sense of self that is derived and perceived from the role we take on in the work we do' (2012, p.563).

As professional identities are constructed and deconstructed over time, they are often interrupted and may be multiple. Cho (2010) and Apesoa -Varano (2007) highlight the link between self, self-concept and professional identity studies. In addition, studies around retention rates in nursing may link negative aspects of nursing as an occupation with low self-esteem and, therefore, low professional identity (Prato et al., 2011; Bolan & Grainger, 2009). It is important to consider this link between professional development and self in relation to learning disability

nursing, as the role and existence of the learning disability nurse has historically been challenged. The literature examined around identity suggests this plays a part in the shaping of the nurse's perception of professional self. Although numbers of studies have focused on the professional identity and professional socialisation of nurses, few have focused on this in relation to learning disability nursing. Recent government policy has firmly articulated the place of learning disability nursing (UK Chief Nursing Officers, 2012). However, a number of studies suggest there have been challenges to the existence of the role; including from nurses in practice, nurse educators, policymakers and those who commission nurse education (Gates, 2010). The history of learning disability nursing appears to have shaped the literature around the value of the learning disability nurse and has focused on role profiles and health outcomes for people with learning disabilities, rather than a focus on the professional socialisation of this group of nurses, which is implicit rather than explicit within the literature.

Nursing is a global, but fluid, socially constructed identity is both collective as a profession, and individual in regard to those nurses who make up the profession. Although these aspects of identity concerning nursing more generally is widely discussed within this field (Lewis, 1998; Hallam, 2002; Keighley, 2006; McKenna et al., 2006; Scholes, 2008), there is still a dearth of literature specifically around the identity of the learning disability nurse. Whilst nursing since the Nurses' Registration Act in 1919 has had separate training for those working with particular groups, the public often perceive there to be one type of nurse, based on the medical model, working in a hospital and caring for ill patients (Mitchell, 1998; Sweeney and Mitchell, 2009). This provides learning disability nurses with a continuing challenge in relation to their professional identity. Understanding who the learning disability nurse is in the context of nursing raises questions of identity, what the public perceptions of nursing are and why an individual chooses to become a nurse, and how this in turn shapes how they see themselves.

## **2.7 Conclusion**

This chapter has offered a contextual background for the place of learning disability nursing in contemporary health care practice based on the literature focused on the

history of care for people with learning disabilities and has explored some of the work underpinning theories of identity crucial to understanding the identity of learning disability nurses. The literature suggests that learning disability nursing has a history that has in part shaped the literature base, as those who develop policy, deliver care and espouse theory publish the evidence base. The evidence base has been changing rapidly within the context of dramatic changes in health care provision for people with learning disabilities over the past 30 years. Literature in learning disability nursing is often written by learning disability nurses themselves and focuses on more general aspects of role, interventions, and policy change; whilst the learning disability nursing literature base is wide-ranging studies that specifically focus on the working lives of the learning disability nurse from a narrative perspective, but are limited. In the context of my study, the literature around identity theories has highlighted some key concepts around the self, individual and group identity, and identity in relation to others. This has not been reflected in the learning disability literature per se but in the more generic literature, it provides a basis for understanding where the gaps may be in exploring the changing identity of the learning disability nurse and their place within the family of nursing more broadly. My study is interested in who the learning disability nurse is and their experience, and therefore the literature focused on career choices and why people choose nursing, and also more specifically learning disability nursing, has provided an underpinning for understanding the narratives of the participants.

The following chapter explores the methodology of the study and its underpinning philosophy, including the development of biographical studies and the narrative in nursing research.

### **3.1 Introduction**

This chapter explores the philosophical underpinnings of the research design chosen for this study, informing the methods chosen for data collection and analysis. The exploration of both the philosophical and practical approaches to this study provide evidence of a rigorous approach to the research process. Corbally & O'Neill suggest that: 'clarifying and making explicit the assumptions underpinning a methodology and method, and the methodological choices made throughout the research, are core features of credible robust research' (2014, p.34).

#### **3.1.2 Choosing the right approach**

The overall aim of this study was to explore the experiences of learning disability nurses over the past 30 years and the impact of policy change upon their working practices and identity as a nurse. In order to investigate this phenomenon, a qualitative methodology utilising narrative inquiry was employed to explore how respondents perceived their role and identity as a learning disability nurse. In considering an approach to this study, I was cognisant of the range of experiences that learning disability nurses may have had over a number of years and the potential of a narrative approach in gathering in-depth data around these experiences. In choosing a particular research paradigm, methodology and method consideration was given to the diverse epistemological debates (Denscombe, 2007; Dyson & Brown, 2006) and their place in relation to both the aim of my research but also my own philosophical standpoint. I wanted to explore the subjective rather than objective experiences of learning disability nurses and, from their perspective, how they make sense of the world of learning disability nursing with a recognition as Denscombe (2007) suggests in his description of Phenomenology 'that realities will differ from situation to situation and culture to culture'. This focus on phenomenology was also cognisant of my own role as a learning disability nurse and researcher as Denscombe suggests, 'from a phenomenological perspective researchers are part and parcel of the social world they seek to investigate' (2007, p.81). Finding an approach both from a philosophical and methodological perspective that

acknowledged the place of the researcher within the research process was crucial in relation to my own position.

In order to embrace the context of learning disability nursing and my own place within the profession as a researcher, careful consideration was given to the research paradigm, methodology and methods to address the research question. Informed by philosophical underpinnings of social constructionism and phenomenology, a qualitative approach was adopted. Phenomenology, whilst not a specific methodology or philosophy, offers an opportunity to approach the research in a way which acknowledges the lived experience of the individual and attempts to understand this subjective experience. Husserl (1859/1938) is seen as the initiator of the phenomenological movement, and later theorists such as Heidegger (1889/1976) reframed the philosophy within a context of hermeneutic (interpretive) dimensions to understand the impact of subjective experience upon the lived experience (Heidegger, 1962).

However, ontological assumptions also embrace theoretical underpinnings of social constructionist approaches, acknowledging the place of history and cultural specificity in creating knowledge (Burr, 1995). Learning disability is a social construct, as is nursing, therefore in a study which focuses on 'being a learning disability nurse' requires consideration of the social constructionist perspective. As part of the decision-making process around research design, I considered the method of collecting data within a narrative frame. Poetic discourse, dance, song, and autobiographical written forms are all identified as methods of collecting narrative data, (Freshwater & Holloway 2007) however, a detailed consideration of interviews and particularly those towards the unstructured end of the spectrum (Wengraf, 2001) appeared to offer the opportunity to engage with the participants in a meaningful way.

### **3.2 Narrative Inquiry**

The term narrative is commonplace in popular culture, used often within literary fields, journalism, and the arts to describe the 'telling of a story'. Within the area of social research, narratives are a source of data in a range of disciplines including



Education, Psychology, Nursing & Medicine (Holloway & Freshwater, 2007). However, it is only relatively recently that narratives have been viewed as appropriate material for research. Emphasis in the post-war period on humanistic approaches to social research have seen the development of person-centred approaches; case studies, life histories or biographies, all of which may contain a narrative element, and, whilst approaches may vary, it is the potential of stories to uncover meaning within people's lives that underpins narrative inquiry. The increase in the profile of narrative methodologies in social research has led to debate and dispute around definitions of narrative (Andrews, Squire & Tamboukou, 2008). Plummer, in explaining life stories, states that 'the narrative can be 'seen as a most basic way humans have of apprehending the world'.' (2001, p.185). Hurwitz *et al.* use the following definition to highlight the potential of the narrative: 'Polymorphous in content, malleable in form and dynamic in expression, narratives are compositions of unfolding meanings which can be discerned and followed by an audience.' (2004, p.1)

There are diverse definitions of narratives within nursing which largely focus on patients' stories as narrative (Thomas, 2010; Corbally & O'Neill, 2014). However, it is also suggested by Corbally & O'Neil (2014) that the classifications of narratives outlined by Ricouer in 1981 as 'operating on two distinct levels: the socio-cultural and personal' (p.35) still stand. The socio-cultural narrative provides a meta narrative of societies, organisations or groups and these 'shape the meaning and experiences of the individual' (Corbally & O'Neill, 2014, p.35). This is important in relation to my understanding of narrative, as the meta narrative of learning disability nursing shapes the narrative of the individuals involved in my study. Narrative inquiry provides an understanding of how personal narratives influence professional narratives, how individuals perceive their role as learning disability nurses and how identity is represented within these narratives. The decision to emphasise or omit particular elements, whether consciously or unconsciously, creates a picture – an identity. The narrative also places the individual within the social world in which their story exists. In telling the story of their career we also see the social and political world in which these nurses function. We not only see them as individuals, but also as nurses within what has been a changing social and political arena for the past 30 years. The dominant cultural narrative of learning disability nursing is created with

reference to society's construction of people with a learning disability, their care, and, therefore, those who care for them. The learning disability nurse narrates their own story against a backdrop of social and political change that we can trace over the past three decades.

The construction of a narrative inherently requires personal reflection. Holloway and Freshwater (2007) postulate that the creation a narrative in terms of the creation of a plot, characters, sequence and meaning, give the researcher a rich insight into both the told and the untold. How the narrator chooses to shape the story, the structure and composition of the story, create a representation from the narrator's perspective, which can then be interpreted from the perspective of the researcher. Ayres & Poirer in Latimer (2009) suggest that the 'secrets' within the story, i.e. that which is left unsaid, has a meaning not only to the narrator but also to the researcher who may use pre-understanding to interpret these 'secrets'. This has particular relevance for this study, as the researcher is themselves part of the same group of nurses and needs to be consciously aware of the assumed secrets when listening to and interpreting these stories. The history of learning disability nursing and the position of the participants as nurses on a professional register may also impact upon what is said and what is left unsaid. The 'choice' to tell or not impacts on the power balance within the researcher/respondent relationship. The respondent's role in the research process constitutes one of empowerment in which the narrative gives the respondent the opportunity to choose what to include in their 'story'. This issue of power balance and the research process is of specific relevance to learning disability nurses as they often occupy a vulnerable place within the sphere of nursing (Mitchell, 2000).

Taking an approach that embraces narrative inquiry within this study enabled me to acknowledge my professional background as a learning disability nurse, and also the ontological assumptions around learning disability nursing as a social construct. If we assume, as discussed in chapter 2, that learning disability as a concept is constructed by society then the nature of learning disability nursing is also socially constructed. The narrative approach offers a framework to support the respondent to share thoughts, feelings and opinions, and, as Corbally states, to 'engage in the creation of meaning in the social realm' (2014, p. 72). Postmodern and post-structuralist views suggest that the interview can be an opportunity for meaning

generation rather than just the reporting of meaning (Holstein & Gubrium, 2004). The narrative interviews may be seen as a space for the interviewer and interviewee to create meaning through a narrative which is set in a context of place, time and the relationship between the participant and interviewer (Holstein & Gubrium, 2004; Wengraf, 2001; Holloway and Freshwater, 2007).

Narrative suppressing methods, for example, what is often seen as the traditional interview with pre-prepared questions, would not generate the data required to understand the experiences of these nurses. In contrast to question and answer exchanges of the traditional qualitative interview, the narrative allows the teller of the story to sequence events and to develop plots and characters. Wengraf (2001) argues that narrative interviews are, however, semi structured, in that the interviewer must be well prepared prior to the interview and that the interview has to be well designed in order for it to be semi structured.

Although, as previously noted, narrative can be derived from a range of media, the focus for this study is 'narrative as story'. The story is a specific form of discourse production, which has structure and components and differs from other forms of narrative, for example poetic discourse (Hatch & Wisniewski, 1995). Using narrative in this way enables the exploration of multiple subjectivities, understanding the 'story teller' through their story, and also the social and political change in the past 30 years.

### **3.2.1 Philosophical underpinnings of narrative inquiry**

In order to develop an understanding of what it means to be a learning disability nurse within the context of this study, we must first explore what it means to 'be' in relation to the narrative. Epistemologically, the narrative provides us both with a way of knowing and a way of telling; it can be used to interpret 'truth' from the perspective of the creator of the narrative. Sarbin (1989) postulates that, as social beings, we construct the stories of our lives as we live them, and develops this further by suggesting that we 'think, perceive, imagine and make moral choices according to narrative structures' (p.8). Lives, from childhood, are shaped through narratives that are used to instruct or inform, to empower, or to 'cathart' (Smith, 2003). Bruner (1991) suggests that narrative reasoning human reasoning alongside scientific

reasoning, not measuring which is more valid but accepting each is different. The telling of a story based on memories of experiences creates an individual reality, which can reflect feelings, thoughts, moral reasoning and judgments. MacIntyre (1981) and others also suggest that narrative is central to our understanding of human behaviour, suggesting that we interpret the behaviour of others through their narratives and recognise our own narrative within the narratives of others (Holstein & Gubrium, 2004; Wengraf, 2001; Gergen & Gergen, 1988; Jones, 2004). In this regard, exploring the experiences of learning disability nurses, the researcher is placed within that context as a learning disability nurse herself and interprets their 'reality' in the context of her own narrative. This has its own benefits and limitations, which will be discussed further.

### **3.2.2 Narrative within social and cultural boundaries**

As Reissman (1993) identifies, stories are not only personal but they embrace the cultural and the social aspects of lives. Bruner (1991) suggests that storytellers do not 'operate in a cultural vacuum' but narrate their stories within the framework of their culture, beliefs and values. Holloway and Freshwater (2007) also suggest that when seen as a social process, narratives also have the capacity to explore issues of power and culture and to develop 'local knowledge'. In exploring the narratives of learning disability nurses, we not only see the social processes at work but can also acknowledge the place of the stories within the culture of nursing and, more specifically, learning disability nursing. Nurses bound by a Code of Conduct (NMC, 2008; 2015) are aware that elements of their story may need to remain untold as they could be perceived as 'unprofessional'. As such, the culture of the 'profession' influences the telling of the narrative. Ramvi, in 2015, in a single-case biographical narrative, examines the self-understanding of a nurse and identified the importance of the professional personal in creating the narrative. Whilst this study came to light post data collection for my research study, it supports the view that the nurse will create a narrative that blends the personal and the professional.

Within narratives of professionals like nurses, where they are relaying experiences over a timespan, there may also be a reluctance to use particular terminology when telling the story of their experience as a learning disability nurse due to changes over

time and not wishing to appear 'politically incorrect'. The narrative, therefore, is created as an individual story but within cultural and social boundaries.

### **3.2.3 Narrative capturing time**

Narratives are also constructed within the context of the life lived and experienced within a specific space and time. The experiences of learning disability nurses within this study are situated within a particular space and time, told today (on the day of interview) they are a reflection of a number of years, for some more years than others. The 'story' is told 'today' but in the context of a period, defined by the storyteller. Gergen & Gergen (1986) describe the story as a movement through time, and it was particularly this movement that the study needed to capture.

### **3.2.4 Narrative and identity**

Smith & Sparkes (2008) suggest that narratives can shape identity and concepts of self. Further to this, Sarbin (1989) and Gergen & Gergen (1986), prior to the work of Smith & Sparkes (2008), suggest that moral choice is also often evident through narrative and stories of 'moral choices' can serve to maintain or enhance self-identity. Padilla & Nelson (2011) note that 'biographies help to illuminate the elements of identity formation of interest to nursing scholars and further the development of the profession;' (p.189) However, they also question whether there is a wider interest in these stories outside of the nursing profession, suggesting that story may be context and content specific. I argue, however, that, while the specific content of the narrative may be in a nursing context, the wider social meanings are evident in discourse around relationships, culture, organisation, and society.

In the production of a narrative, an identity is created for the individual narrating the story, but a perception of the wider social context in which that narrative takes place is present. The place of people with learning disabilities in society and, therefore, those who care for them, is evident within the story and the story is shaped by this social context. This constitutes a wider narrative than that of the individual – the story of learning disability nursing as a narrative in its own right, a collective, cultural and social meta narrative, is created by the individual narratives that make up that group of nurses and is also validated by the literature outlining the history and culture of learning disability nursing.

The narrative takes us beyond the seen world and allows the researcher to see the interaction between the participant and their world, revealing the interconnections and cultural influences. When we organise our lives into narrative structures we then assign meaning to them through the telling of stories, revealing the internalised world as well as the external. The experiences of learning disability nurses told through their individual narratives also reflect a group narrative of what it means to be a learning disability nurse and represent internalisation of the many changes to care of people with learning disabilities.

My interest within this study focuses on the changing story of learning disability nursing, the potential influence of changing policy and societal attitude towards people with a learning disability. This interest in understanding the story of learning disability nursing from the nurse's point of view led me to further explore narrative methodology.

### **3.3 Developing the concept of unstructured interviews: the case of Biographical Narrative Interpretative Method**

Acknowledging the movement towards biographical approaches (Chamberlayne et al, 2000), Biographical Narrative Interpretive Method (BNIM) offers a framework for understanding the complexities of the narrative. BNIM draws on a number of theoretical perspectives in order to take a case-based approach to narrative analysis. Its approach includes narrative interviews and an interpretive analytic approach to cases generated through the interview techniques (Wengraf, 2001; 2008). Within the BNIM approach to data collection, the interview is seen in two (sometimes three) phases. The biographical narrative phase in phase one offers an open structure led by the interviewer with a single statement to elicit the narrative, allowing the individual a free flow of information, memories and their 'story'. This single statement is known as a Single Question aimed at Inducing Narrative (SQUIN). Rather than being constrained by interview questions or probes to direct, the respondent is free to tell as much or as little of their story as they decide without interruption, allowing memories to surface and connections between thoughts to develop.

Phase two occurs after a break of around 10-15 minutes and, during this break, the researcher reviews their field notes and develops statements to use in phase two to develop further Particular Incident Narratives (PINs). The second phase generates rich data around incidents prompted by the researcher but chosen by the respondent. Phase three within BNIM is not always present in studies, but does allow an opportunity for the researcher to follow up more specific points (Wengraf, 2001) and to be more directive with questioning, should this be appropriate.

BNIM also incorporates an interpretive strategy in order to interrogate the data gathered within the interviews in a very specific way. Each narrative creates a 'case' to be analysed using a two-track method in order to analyse the 'lived' and the 'told' experience. At its fullest, there are nine stages of analysis, utilising panel analysis in addition to individual analysis (Wengraf, 2001; 2008; Corbally, 2014). However, it is possible to use the interview technique to collect data and use a different analytical strategy (Wengraf, 2001). For my study I chose to use BNIM interview techniques and not the analytical framework, returning to them-based narrative analysis due to the numbers of participants within my study (20 is a much larger sample size than the much smaller numbers in BNIM based studies). Additionally, the layers of interpretive panel stages within the purist approach to BNIM lend themselves to the small case-based examples, incorporating additional layers of interpretation and different people interpreting the narratives (Wengraf, 2001; Jones, 2004; O'Neill, 2011).

There are a few notable studies utilising BNIM as a methodology within nursing or health care and Corbally & O'Neill (2014) suggest that there are 'similarities between the daily practice of nurses and BNIM which may create a particular resonance with prospective nurse researchers' (p.35). An early study utilising the method by Jones (2004) explored the identity of informal carers. This study influenced the choice of method for my study as I appreciated the depth of narrative gained from utilising this interview technique, but also the potential to give voice to the participants through a less structured interview technique. However, the sample numbers, in keeping with BNIM studies, were small and this raised concerns around ensuring I was able to represent learning disability nursing from across England and across a 30-year time span. I sought further studies using this method, however, in nursing, none had used

the interview technique with larger numbers. I, therefore, sought advice from Tom Wengraf, who was able to guide me around the use of the interview technique in order to build this into a narrative inquiry approach utilising narrative analytical approaches (Wengraf 2009, Personal communication).

After consideration of a wide range of interview-based methods within a narrative inquiry approach from the structured to the unstructured, the approach to data collection within this study was informed by the philosophical underpinnings of a narrative approach and the desire to ensure the voices of learning disability nurses themselves were heard as part of a 'negotiated encounter' (Russell, 2012) between myself and the learning disability nurses within the study.

### **3.4 The research process**

The method used for this study did not facilitate large numbers, but, in keeping with other forms of qualitative data generated through face-to-face interviews, the numbers are small. For the purposes of this study, the sample size was 20 learning disability nurses registered with the Nursing & Midwifery Council who had been working with people with learning disabilities in the past 30 years in England.

In order to meet the research objectives identified for this study whilst utilising a biographical narrative approach to the interviews the following Single Question Aimed at Inducing Narrative (SQUIN) was used:

*As you know I am interested in the experiences of learning disability nurses over the last 30 years. Please tell me about your career as a learning disability nurse starting from when you began to think about your nurse training to now.*

In order to gain rich data using the methodology I needed to be cognisant of the issues around numbers of learning disability nurses working inside and outside the NHS at the time of data collection. As a learning disability nurse academic at the time, I was aware of the impact of changes in service provision across England. There had been an overall decrease in the numbers of learning disability nurses, not only appearing on the NMC register (NMC, 2010) but also a change in commissioning over around a decade reported in the literature by a number of commentators (Gates, 2009; Barr & Gates, 2008) and changes in the places in



which learning disability nurses work in a wide variety of non-NHS workplaces (Gates, 2010). Data from the NHS information centre in 2009 suggested that only around 6,600 learning disability nurses were working in the NHS at this time. Whilst biographical narrative studies do not necessarily concern themselves with representative sampling, it is important to acknowledge that, whilst the numbers in my study were small, they came from nine counties across England and included nurses working in a variety of settings.

#### **3.4.1 Population target**

Those nurses working in Scotland, Wales or Northern Ireland were excluded from the study in order to retain a focus on England, as the health and social care policies across the countries in UK can vary. The following were also exclusion criteria for this study:

- Lack of consent given to participate in the study
- Those nurses who have not maintained their registration with the NMC or those who have maintained their registration but who have not been working with people with learning disabilities in the past 30 years.
- Inability to respond to an interview conducted in the English language.

#### **3.4.2 Engaging the sample**

It had been recognised that a large percentage of learning disability nurses did not work within NHS settings and many, although registered with the NMC, were not currently in roles acknowledged as nursing roles. For the study it was important to capture the experiences of not only those nurses working in NHS settings but those who were not. This led to a challenge in relation to recruitment of nurses who may not be located through regular modes, such as union/professional body membership or through NHS Trust locations. As it had become clear that nurses were working in a diverse range of settings, many were still accessing online forums for support and discussion, so the sample were recruited by advertising within online professional networks via social networking sites. A number of online forums exist and these have an advantage of encompassing those learning disability nurses working in a diverse

range of settings and, as the original intention had been to use web-based discussion as a follow up mechanism for the interviews, those who are already utilising web-based discussions. It has been a view held and supported by researchers that the population of those that use the internet is skewed in favour of the young, upper middle class and well educated, and therefore questions around the validity of samples drawn from this population have been articulated for some time. However, as Hewson et al (2003) note, the growth in internet use over the past decade has changed this view somewhat and the profile of populations who use the internet and web 2.0 technologies has changed.

An invitation (appendix 2) was posted on the appropriate online forum and this was followed up by personal invitations via email to take part. The invitation letter (appendix 3), participant information sheet (appendix 4) and consent form (appendix 5) were emailed to those interested. 'Snowballing' was also used, where potential participants highlighted individuals who may also be interested in the study. Those participants contacted via a third party were sent clear details of why they were being contacted and who the initial contact was.

### **3.4.3 Ethical issues**

Ethical approval for the study was gained through De Montfort University Faculty of Health and Life Sciences Ethics Committee (see appendix 6). The learning disability nurses in the study were accessed through a variety of online based forums and, whilst on the NMC register and working as learning disability nurses, this was not necessarily in NHS settings and, therefore, there was no requirement to seek approval via the National Health Service Ethics Committee.

Ethical guidelines exist in a variety of forms and, for the nurses involved in this study, the NMC Code: Standards of Conduct, Performance and Ethics for Nurses and Midwives (2008) was an underpinning ethical framework. Additionally, research governance frameworks (DH, 2005) assisted to ensure standards of ethics were adhered to for the study.

Written consent was gained by the researcher prior to the arrangement of the interview via email. The consent form was sent to all participants via email, and a hard copy of the consent form was also taken to the interview to be signed by the respondent, with clear information within the participant information sheet that consent may be withdrawn at any time, both during and after the interviews, with no repercussions for the respondent.

### **3.4.4 Anonymity and privacy**

All individuals were initially given a code identifier and they later agreed a pseudonym. Any material related to that individual was then identified using that pseudonym.

The world of learning disability nursing, however, is a small world and it has been made clear to participants that, wherever data may be presented publicly, any potentially identifying information would be removed. This include people's names, place names, and areas where the participant had asserted that they were wary about how their data would be represented through using phrases such as 'be careful how you write this one'. Potentially sensitive data and that which may identify the individual was highlighted in the transcription when returned via email to the

participant, and they were asked to review this and amend where appropriate. Beyond the obvious identifiers, such as people and place names, there was sensitive data that needed careful handling within a relatively small professional group. One participant had a terminal illness that had been publicly shared in a variety of settings prior to the study. The illness was a key part of her story and she was happy to share this during the interview, but when presenting initial findings at a conference it was crucial that her data was presented in such a way that she was not recognised to enable her to maintain her anonymity in that setting. Participants in the study have been able to maintain a connection to the researcher and to the project throughout.

### **3.5 The researcher position in the research: shared understandings**

The position of the researcher in relation to the research topic and the participants is a crucial consideration. As a learning disability nurse working in an academic setting, whose chronology of nursing spanned the 30 years focused on in the study, this positioning required reflexivity in approach in order to explore the influences of one's own social reality on the data collected. Issues of power relationships needed to be considered and addressed as far as they possibly could. Additionally some of the participants were known to the researcher and some were not, the methodology here being important in acknowledging and ensuring any potential negative effects of this were mitigated against. Narrative research, particularly using a minimally structured approach, has been suggested and offers the opportunity to shift the power balance and empower participants to tell their story. BNIM also places the researcher in listening mode, as the first part of the interview takes place with no interruptions and just non-verbal encouragement, and, during the second part, the researcher, repeats back the phrases used by the participant when seeking expansion of aspects of the narrative (Wengraf, 2001). It was observed that for those participants who knew the researcher, phrases like 'you know what I mean?' were frequently used in the narrative, these were responded to with a non-verbal nod. There were challenges to this type of interviewing style for both the researcher and the participants who knew me, in that it felt uncomfortable at times, as if in a one-way conversation with someone who knew there was a shared understanding and history. This was less apparent for those participants who did not know the researcher, as they narrated their story without knowledge of a shared history. All participants were given an

explanation of the interview technique prior to the commencement of the interview and this appeared to aid understanding of the process. Shared histories and understandings can enhance data (Leicester, 1999; Oakley, 1981) through what Stanley (1993) describe as 'epistemological privilege'. These shared understandings may also shape the narrative in relation to what the participant chooses to leave out of their story; shared understandings of Codes of Practice or unwritten codes of behaviour may shape the story as participants choose to present themselves in particular ways (Goffman, 1978). The elements of the story which are untold, it can be argued, are just as important as the told story (Wengraf 2001).

Throughout this study my key focus had been on ensuring the 'voice' of learning disability nurses was heard whilst recognizing that this is my 'voice' too. Choosing a method therefore that acknowledged my place as a researcher but also as part of the community I was researching was crucial. My role as researcher in the context of this study has been a privilege and also a challenge as a learning disability nurse who has also 'lived' the history described by the study participants. A reflexive approach throughout the process of undertaking the study allowed me to check my thoughts, assumptions and feelings as a learning disability nurse, to acknowledge and to challenge some of these. Identifying as a learning disability nurse with over thirty years of experience early on in the research process enabled me to explore research methods which would not ignore my position as a nurse but ensure that these were acknowledged and accounted for to ensure rigour and validity within that process. Having a supervision team made up of non-nurses and an advisor who is a learning disability nurse also allowed me open up discussions for challenge and the team provided another check for any assumptions I may have made.

There were numerous reasons why a narrative approach to my study was chosen, with two key reasons chosen. Firstly, there is a paucity of this type of research using these methodologies as, whilst learning disability nurses may write about their practice, there is less written about the practice of learning disability nursing from a narrative perspective. The stories of learning disability nurses as a group have not been subject to narrative analysis and there are few studies using biographical or autobiographical approaches to careers of learning disability nurses. This study would contribute to the small body of research in this area and therefore represents

an original contribution to the knowledge base. Secondly, the narrative helps us to understand professional practice, both in learning disability nursing, and in education, as we seek to understand who these nurses are, their identity and their career trajectories.

### **3.5.1 Communication with participants through the life of the project**

A 'blog' for which all participants have the link ([www.nickyphd.blogspot.com](http://www.nickyphd.blogspot.com)) was maintained by the researcher for the first five years of the study, which automatically updated to a 'Facebook' page through which participants could follow the progress of the project at any time. No identifiers were used within the blog, relating more generally to theoretical and methodological issues than to specifics. Ownership of the domain on which the blog sat changed in 2013 and I am now unable to maintain and update the blog. All participants remain in contact with me, however, either through social media or through email contact. The findings and various stages of the project have been presented at conferences annually, and it has been important to me to be able to update the participants on where I am presenting the study findings, maintaining my view that these stories ultimately belong to the participants.

## **3.6 Data collection and the research design**

Generally, studies using this method have used 'face-to-face' interview styles in the first and second phases, and the third phase, where present, has been conducted either face to face or electronically. The design for my research study using this approach had a third phase developed that consisted of an online synchronous communication route using an instant messenger system. This was agreed with the participants and telephone contact following initial analysis was to be used to arrange the phase three interview. Although participants were made aware at the beginning of the phase one interview that this online opportunity would be available, there were a number of issues that arose from the development of this phase. Whilst online interviews are used in a variety of research fields, the use of social software, such as instant messaging services, to undertake these interviews was relatively new and experimental (Denscombe, 2007). The researcher was to ensure that data from phase three (online) interviews is saved as a data file and held on a secure server. The interviews were to take place over a secure network and in an area

where the connection is strong and reliable. This location would also be private, with no opportunity for others to view the 'conversation' on screen. The participant was made aware of the process that will be followed should the interview be interrupted in the case of power or connection problems. However, following testing of this approach it was unsustainable as firewalls within organisations blocked the use of all synchronous messenger systems. Although 'Skype' was enabled in some organisations, not all participants were able to use this. A decision was taken to offer asynchronous opportunities for further data collection via email should any participant wish to take part in this. Following the interviews in phase one and two, all participants felt that they had provided the data they wished to therefore did not engage with email exchanges for this purpose.

### **3.6.1 Methods of data collection: the pilot interviews**

Two pilot interviews using the BNIM interviewing technique were carried out and transcribed in July 2009. The benefits of undertaking this were immense. I was able to test not only the BNIM interviewing style but also the process surrounding the interview, timing, location, recording equipment, participant information sheets, consent forms, and the safety arrangements. The interviews revealed that, at the beginning of the first phase, there needed to be a clear explanation of how the interview would proceed, as many participants may be unfamiliar with the technique and the open, free-flowing, nature of the approach. Following the pilot interviews, I produced a script for my opening of the interviewing which outlined that I would listen to the whole narrative and not interrupt, and that they could take as long as they chose. I also included the fact that there would be a break between phases one and two to enable note taking, comfort breaks, and the preparation for phase two.

The first of the two interviews was very short in phase one, as the participant stated afterwards that she wasn't sure how much detail there should be and wasn't sure what I was interested in. However, phase two enabled me to draw out particular incidents which could then be expanded upon.

Following transcription I was offered feedback from Tom Wengraf, who received the transcription and provided critical feedback. This enabled me to practice the technique further (outside of the research study) to become more familiar with the

interviewing technique. I practiced this with colleagues but also asked a colleague who had been trained in BNIM interviewing to interview me to gain an insight into the BNIM interview process from the perspective of the participant.

### **3.6.2 Data Collection: Conduct of interviews**

Interviews were arranged in a mutually agreed location, for some this was a room within their workplace or their home or a location felt to be appropriate in relation to privacy and safety. Safety procedures were followed in accordance with the Social Research Associations Code of Practice for Social researchers (Social Research Association, 2006). These procedures specifically include using telephone contact prior to the interview to arrange the location and, wherever possible, for the interview to take place in a private room in a public place. Where interviews were carried out within the participant's home, the researcher used information about the surrounding area and safety to ensure that they are safe in that area. A key person was telephoned prior to the interview with details of anticipated time to be spent during that interview. At the end of the interview, the key person was then telephoned to confirm that the interview had finished. Additionally, the key person was given a list of interview locations. The researcher was identified to the participant using their University ID badge. The participant information sheet also contains details of the line manager of the researcher who may also be contacted at any point to confirm identity.

Interviews were carried out using an unstructured format following the framework of Wengraf's (2001) Biographical narrative interpretive approach. Each interview followed this sequential pattern:

- Introduction and establishment of relationship between researcher and participant.
- Completion and confirmation of written consent to participate, and for the use of audio recording equipment and the taking of field notes. The participant was also reminded at this stage that, as a Registered Nurse, the researcher is bound by the NMC Code of Conduct and, should poor practice, abuse or neglect be identified, this may need to be reported.



- The interview then continued with the initial question (SQUIN):

*As you know, I am interested in the experiences of learning disability nurses over the last 30 years. Please tell me about your career as a learning disability nurse, starting from when you began to think about your nurse training to now*

- Following the initial narration, which took anything between 10 minutes and an hour, a break of around 10-15 minutes enabled the participant to relax and the researcher to review the field notes in order to prepare Topic questions aimed at inducing narratives (TQUIN). The second phase of the interview generally lasted anything between 30-60 minutes.
- At the end of the interview the participant was thanked for their participation and their contact details for follow-up interviews checked as accurate.

Following each interview field notes were written up, including a 'general impressions' note for each participant. This, as advocated by Wengraf (2001; 2009), aids memory recall. In relation to data security and confidentiality, the audio recording from the interviews were transcribed verbatim and all data will be kept secure as digital files on a password-protected server, and, in the case of field notes and consent forms, in a locked filing cabinet in the researcher's office on University premises. All completed transcripts were returned to the participant for checking.

## **3.7 Presentation of findings**

### **3.7.1 The participants**

The importance of understanding who the participants are and not losing sight of their lived story is highlighted by Wengraf (2001) and Holloway and Freshwater (2007), amongst others. Within a qualitative study write up, fragmented quotations may be used in the findings' chapters, which do not illuminate or paint a full picture of who the participant is. Whilst this is not offered as a criticism of studies that take this approach, I felt strongly that my study should offer the reader an opportunity to read the story presented to the researcher (and not just as an appendix). All 20 participants are crucial to the creation of a narrative of learning disability nursing,

therefore each of them is presented as a 'vignette' in chapter 4 as suggested by Holloway and Freshwater (2007), Holloway & Jefferson (2008) and Wengraf (2001).

### **3.7.2 The interpretive task**

Although a number of approaches to narrative analysis exist, one of the underlying principles is, as Reismann (1993) states, the method uses the story itself as the object of enquiry. The perceptions of their own reality are evident within the participants' stories and it is this that forms the basis of the analysis. She also notes that, equal to the structure and content of the story, is the way in which the story is told. Within this study, narrative structures provided by participants reveal storylines in which key themes emerge around the journey to becoming a learning disability nurse, working lives, and change. Roberts (2002) suggests the process of thematic analysis begins with the careful reading and re-reading of the texts to identify and form connections between themes. In accordance with philosophies of hermeneutic phenomenology, the aim of the analysis is to move beyond the describing of the lived event to the interpretation of those experiences (Flood 2010), how the story was told, the relationship between the researcher, and the participant all have a crucial part to play in narrative analysis (Holloway & Freshwater, 2007; Flood, 2010). The hermeneutic circle, as described by Gadamer (1976), is evident in the approach to analysis taken within this study as the researcher identifies with the lived world of the participant and becomes part of that through the analysis of the narrative. In seeking an approach to interpretation within his proposed Biographical Narrative Interpretive Method, Wengraf (2001) offers a distinction between the life history and the life story reconstructed into a 'two layered biographical structure' (p.232).

This study encompasses Wengraf's approach in a non-purist form, in that the layers of biographical structure encompass that which is told and that which is observed. Learning disability nursing has a history which has changed dramatically over the past 30 years, and the stories that are told are also observed both in relation to the researcher's own history and understanding of learning disability nursing, and also the history documented elsewhere. The narrative is, as Wengraf suggested, a 'creative transcription' consisting for this study of the actual interview and memos of thoughts, feelings and notes of observations. All of these elements form part of the narrative to be interpreted. Theories of interpretation articulated by Ricoeur (1971)

have influenced the stages of analysis within this study, moving from early reading of the transcribed texts to the 'clustering' of themes identified and detailed exploration and analysis. Choosing a specific analytical framework was not without its challenges, however, that of Rosenthal and Fischer-Rosenthal (2004) was finally chosen to enable me to use a staged approach to analysis of the narratives, including the analysis of biographical data, thematic analysis, reconstruction of a case history, analysis of individual, comparisons between life lived and the narrative, and the formation of different kinds of narrative.

### **3.8 Data analysis**

Within the study data is made up of two key elements, the 20 transcribed interviews and the interview notes following each interview written by the researcher. Ten of the 20 interviews were transcribed by the researcher, the remaining 10, due to time constraints, were undertaken by an experienced transcriber. To ensure immersion in the data for all participants, the audio recordings for the interviews were held on an additional password protected playback device, allowing the researcher to listen to these and to 'hear the data', even whilst the original audio recordings were with the transcriber. The first listening to the interviews also included the additional notes added to post-interview memos or observations. Wengraf (2001) sees this as crucial to the data collection process, as this first listening acts as stimulation for memories of additional observations and thoughts that, in subsequent listening, would be lessened. Wengraf feels strongly enough about this to suggest that transcription could be delayed in order to ensure that this stage is not lost 'the tape will always wait patiently to be transcribed, the ideas that spring from you as you write will vanish quickly' (2001, p.210).

First listening post-interview therefore incorporated this stage, however, further listening to the interviews, whilst either doing or waiting for transcription, enabled the researcher to spend time focused on the nuances of the individual narrative which may have become lost following written transcription. During this process, notes were added to the post-interview observations of each individual, building a pen picture to go alongside the individual narrative. Following transcription, the observational or reflexive notes were added to the text in side margins using a word processing package.

Once all interviews were transcribed, a staged approach utilising the framework suggested by Rosenthal & Fischer – Rosenthal (2004), to analyse these transcriptions, was followed. The transcribed interviews for all participants were read and re-read individually alongside notes and observations to create a pen picture or history of the individual, with chronological details identifying the route through their career; the lived life (Wengraf, 2001; Breckner, 1998). This focus within the BNIM method enhanced my approach to individualism within the study, as I was conscious of not losing anyone's story or voice. The development of cameos or vignettes enabled me to maintain the connection with all the participants when moving onto the stage of analysing the themes identified across the narratives. The process of thematic analysis for this study was informed by the work of Ricouer (1981), in addition to being mindful of the work of Wengraf (2001) and others (Rosenthal & Fischer–Rosenthal, 2004).

Analysis of each individual narrative in relation to the lived story was followed by identifying themes within the narratives of all participants; early themes included their journey to becoming a qualified learning disability nurse and descriptions of working lives, including relationships with others and change. A coding approach was utilised which identified quotations within each theme and sub theme. This coding process was aided using a basic computer-based package or word processing and database management, rather than a specific data management package such as nVivo, as, whilst these packages were considered, the researcher felt it offered no additional advantages over the packages being used and had the potential to decontextualise quotations (Holloway & Jefferson, 2000). Additionally, all transcripts had been mapped onto templates designed for use within the BNIM, which offered opportunities for hand coding. Within the purist approach to BNIM at this stage, case histories and micro analysis of these would have taken place with others outside of the research process, however, it was not the intention of the study to use the method beyond the data collection stage and therefore narrative analysis continued outside of the method. This approach was checked by the researcher with Tom Wengraf, who suggested that there were numerous studies utilising only the data collection element of the method.

In accordance with the principles of thematic analysis, the themes identified informed the data to be included within those themes. Subsequent coding into those themes and sub themes highlighted data to be included, but also that which was seen to be noteworthy (Wengraf 2001). Individual narratives and their themes were further analysed in the context of the history of learning disability nursing to create a further collective narrative of learning disability nursing.

### **3.8.1 Trustworthiness, credibility and authenticity in the research process**

It is acknowledged within qualitative research there are a number of approaches to scientific rigour in the research process. Truth is often at the heart of this debate and it is suggested by Holloway & Freshwater that this truth within narrative studies is a snapshot of that moment in time and based on the truth for that particular individual at that moment in time. It is therefore more applicable to use notions of trustworthiness, credibility and authenticity to 'reconceptualise' validity and reliability (Lincoln & Guba, 1985; Guba & Lincoln, 1989).

Trustworthiness, according to Lincoln & Guba, was composed of dependability, credibility, transferability and confirmability (Lincoln & Guba in Holloway & Freshwater, 2007). In the context of this the study these areas have been explored in order to satisfy validity and reliability. Dependability is based on the narrative of the researcher, the consistent and dependable approach to the research process, and the articulation of this. Being reflexive throughout the process enables this to be articulated, with decisions being clear to the reader. The keeping of a reflexive diary and blog encouraged this reflexivity within the study. Credibility is linked to internal validity in that the representation of the narrative is true to its original meaning and the reader should feel the account is plausible (Holloway & Freshwater, 2007). Within this study this was encouraged through the sharing of transcripts and the researcher's interpretations for discussion within the supervision team. This enabled any challenges to interpretation to be fully discussed. Transferability, as suggested by Lincoln & Guba, occurs where the findings within a specific context would be meaningful to others in a similar context. The researcher, on a regular basis, tested this by sharing interim and the final findings at professional research conferences (see appendix 7) and receiving feedback from other learning disability nurses that supported transferability. Confirmability relates to the evaluation and confirmation

that the aims of the study have been met by the conclusions and findings of the study. Part of the process of undertaking this study has been ongoing supervision and advice to ensure the aims of the study are met through the chosen methodology and subsequent choices of analytical frameworks.

Authenticity within qualitative research, it is suggested, is composed of fairness, ontological authenticity, educative authenticity, catalytic authenticity, and tactical authenticity (Holloway & Wheeler, 2002). Fairness is judged through the approach to the participants, including ongoing informed consent illustrated within this study as participants are offered the opportunity to not only opt out at all stages but contact is also maintained in order for participants all to feel part of the study throughout. Authenticity within the study related to the adequacy of the research process but also the participants' involvement in a process of narrating their journey into nursing, their feelings, and their experiences through a biographical narrative approach with a minimally structured interview encouraging insight into their own situation and their future. This was evident with a number of participants who described the interview process as 'cathartic' or 'valuable for reflection', and one participant who felt she had a 'view about where she wanted to go in the future'.

### **3.9 Conclusion**

This chapter has explored the philosophical and methodological basis for this study, focusing the methods chosen in order to meet the aims of the study. In addition, the process of data collection, analysis and interpretation are described in order to understand the findings of the study.

## ***Chapter 4 Findings***

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### **4.1 Introduction**

This is the first of three chapters that detail the findings of my study. In this chapter, we ‘meet the participants’ of the study who are presented in vignette form with a combination of a precis of their career narrative and observations taken from my field notes at the time of interview. This approach draws on the work of Wengraf (2001) in relation to Biographical Narrative Interpretive Method, in that it is the creation of a ‘case’ to be analysed enabling themes to be identified within and then across cases. The use of vignettes to present findings in research of this nature was also supported by Holloway and Jefferson (2008) and by Freshwater and Holloway (2007) as an opportunity to enable the reader to understand the participant backgrounds.

Table 1 is a brief summary of the participants’ data around year of qualification as a learning disability nurse, their role at the time of interview, and whether they were working in NHS or non NHS settings. Data presented in this way highlights the timeline that form part of this project, the 30 years between the publication of the Jay Committee report in 1979 and 2009 when the study began. Whilst all of the participants who took part in the study were registered as learning disability nurses on the NMC register, their roles vary, both in relation to title and in relation to the service context of NHS or non-NHS provision. This diversity was not pre-planned as part of the selection criteria, but came naturally out of self-selection.

**Table 1 : Participant Data**

<b>Pseudonym</b>	<b>Year of qualification</b>	<b>Role</b>	<b>NHS or non NHS</b>
<b>Tina</b>	1965	Retired Nurse	Non
<b>Mary</b>	1974	Retired nurse lecturer	Non
<b>Robert</b>	1980	Community team manager	NHS
<b>Lorna</b>	1981	Public Health Specialist	NHS
<b>Karen</b>	1982	Nurse lecturer	Non
<b>Paula</b>	1984	Locality manager	NHS
<b>Matthew</b>	1985	Company Director	Non
<b>Annette</b>	1987	Deputy Care manager	Non
<b>David</b>	1987	Modern Matron	NHS
<b>Jane</b>	1989	Community Nurse	NHS
<b>Martin</b>	1991	Nurse (assessment & treatment)	NHS
<b>Quinn</b>	1992	Lead nurse (Community team)	NHS
<b>Dean</b>	1996	Programme Lead (Commissioning)	NHS
<b>Ryan</b>	1998	Practice development Nurse	NHS
<b>Julie</b>	2002	Nurse ( Child & Adolescent Mental Health Services )	NHS
<b>Narisa</b>	2004	Acute Liaison Nurse	NHS
<b>Debbie</b>	2006	Health facilitator	NHS
<b>Angela</b>	2008	Developmental Charge Nurse	Non
<b>Jenny</b>	2008	Team Leader (supported living)	Non
<b>Wendy</b>	2008	Ill health retired nurse	Non



## **4.2 Cameos of participants**

Field notes taken at the time of interviews act not only as an aide memoire but also as data (Wengraf, 2001), as the notes are used alongside the transcripts from the interviews to form a meaningful narrative (Emerson et al 2011) and to place the reader in the centre of the experience (Yanow et al, 2012). In forming a narrative, the field notes encompass the feelings of the researcher, the responses of the participant, and the impact of the environment. Jarzabkowski et al, (2014) suggest: 'Field notes are not simply aide memoires to what was said. Rather, they contain the researcher's lived experience of a particular moment—such as the atmosphere of a room - which is not easily captured in recordings' (p. 276).

These observations by the researcher form a part of the narrative generated from two different aspects – the field notes and the recordings of the verbatim conversation. These cameos embed the first impressions of the participant, a summary of their lived lives, and reflections of the researcher upon the interview.

### **Tina**

My interview with Tina was arranged in the afternoon at a pub close to where she lived. It was quiet and we were able to find somewhere where it was easy to speak and to record the conversation. I had met Tina earlier in my career and was familiar with the places she had worked in as a qualified nurse. She was also aware that I knew many of the people who had worked within the long-stay hospital where she had spent much of her career. Tina had made me aware of some health issues that were under investigation for her prior to the interview and noted that this might distract her a little. She told her story openly and easily, using a large number of references to people that she knew or assumed I would know.

Tina had qualified as a learning disability nurse in 1965, the longest-serving of my participants. She had retired earlier in the year before the interview but had been undertaking some 'casual' work. Tina had started her training before the 30-year timespan my study focused on, she had, however, been in learning disability nursing for the period between 1979 and 2009. Tina came into her training at a time when all student nurses were employed by the health authority and hospital, trained in a

school based in the hospital, and then remained within that hospital after qualifying. Tina also undertook what was then known as the 'integrated course', which was a dual nursing qualification in learning disability and mental health. The course was six-12 months longer than a single qualification and often met the needs of local employers, who had a number of people within their services who had both a learning disability and mental health condition. Tina describes the large mental health hospital she worked in as being around 1,750 beds with a matron and assistants on each ward, highlighting the medical model in place at that time:

*'Course you had matron and her two assistants that used to do at least once a day rounds or two but they'd got more patients and she knew everybody, staff, patients and you know it was you did sort of really feel part of a big family*

However, much of her focus in the narrative is on people; the patients she worked with and their social lives, and the staff and theirs. Tina talked about working on a children's unit prior to the 1971 Education Act and the children who were unable to attend school due to their disabilities. Soon after qualifying and working in the large long-stay hospital for people with learning disabilities, Tina moved to the local large hospital for people with mental health problems and stayed there for around 10 years before returning to the learning disability hospital. Tina speaks of trying to bring about change prior to the 1980s and the introduction of philosophies of normalisation and social models of care. Buying the patients their own bedspreads was seen as avant garde, and attempting to change routines frowned upon. Tina also talks about a difficult time when she was suspended from work due to an irregularity in financial accounts. She does describe this with too much concern, as she notes that it was a small matter of something 'not being written down'. Her career as a learning disability nurse within a large NHS Trust involved a number of moves and lots of change. At the end of her career, she decided to retire early without her full pension as the changes had challenged her values too much when her final task was to be involved in another unit closure. At the time of interview, Tina had been doing some agency shifts before retiring completely.

The interview with Tina had been open and friendly. There were many references to named individuals and to places of work, highlighting the assumption that I would 'know' these people and places. I felt that this gave Tina a perceived 'connection'

with me through the people and places we had shared understanding of. Within the narrative Tina described a very difficult time when she was suspended from practice pending an investigation, and I observed that she told this element of the story in a very 'matter of fact' way with no concern in her tone or reluctance to expand the narrative in this area. My overall impression of Tina was of someone with many years of experience and who, reflecting back on her career post retirement, was comfortable in the decisions she had made, the care she had given, and acknowledged it was 'of its time'.

## **Mary**

Mary chose to meet for the interview at her house. I had known Mary for some years so she said she felt comfortable with this. Mary had a long career in learning disability nursing and told her story largely using a linear progression. She appeared very comfortable telling her story but focused completely on her working life and left out all references to aspects of her personal life seen in other participant stories. I perceived this to be due to our relationship and that I would know many aspects of her non-working life.

Mary is a recently retired lecturer who now runs her own business and qualified as a learning disability nurse in 1974. Starting as a 'cadet nurse' in 1970, Mary had originally wanted to be a general nurse. Cadet nurse training at that time enabled younger people to undertake a hospital-based course with work experience in order to then enter nurse training. Mary has distinct memories of first arriving at the hospital for the start of her cadet training. When describing this, Mary said:

*Well I remember it, I do remember that day, it was raining and the first place I saw was Mansion House and it was something like I'd seen in the house of horrors really, it was scary but I went for the interview with the then matron and everybody seemed really friendly and I got taken around the wards, by.. I can even remember the charge nurse that took me round, actually he was an enrolled nurse and he was in my student group later to do his registration, yes and everybody was playing with the kids and that when I walked round and it just seemed, it felt right and I know that's not a very academic statement (laughed), but it just felt right, yes.*

Mary went on to undertake what was then known as integrated training, which combined learning disability and mental health nursing. After qualifying, Mary worked

through from staff nurse, to deputy Sister, then Sister, within a large long-stay institution. In 1977, Mary moved into nurse education and worked as a clinical teacher within the School of nursing. However, by 1979, she was missing working in practice and went back into a Sister's post; working with children within the local long-stay institution. She was very aware of policy at this time and the need to move children out of hospital, and described being a key part in shifting thinking in the hospital around this:

*Because the national development group were visiting at the time so I was very aware of Peggy Jay, National Development Group, and they actually did come to (named hospital) and I'd already read the Jay report and the influence or the comments that Jay had made, particularly about kids not being nursed in hospital. I'd already read Maureen Oswin's book I think at that time about the care of kids not being cared for in hospitals, so it was all made very easy to be creative and innovative*

Involved in moving children out of long-stay hospital care, Mary acknowledges this was not easy. Mary worked in a number of units within the local NHS provision until 1987, when she returned to a nurse education role, as a nurse tutor. Mary remained in this post, undertaking a variety of roles and academic qualifications, until 2008 when she retired. Following retirement, Mary started her own business, training staff in issues around learning disability.

Although I had known Mary for many years, I had never heard the story of her career. Her reputation as a nurse had been one of a formidable character always pressing for change, and her narrative reflected this. There were many examples of her 'remembering' particular incidents or elements of story and skipping back to these. She was able to remember in-depth events, and also how these made her feel, and shared this. The overall impression of her narrative was of someone who had worked in some of the most difficult settings with some of the most difficult staff, but her underlying 'plot' within the story was one of challenge and change. On a number of occasions she said 'it didn't challenge me enough' when talking about the places she worked and why she moved on from them. She also used the phrase 'innovative' often within her narrative, describing her own practice and that of others.

## Robert

I met Robert for interview in his office within his workplace after a four-hour drive. It was a sunny day and he had door open onto a large grassed area. He was friendly with a challenging approach to both the style of the interview and to the questions that became part of the second phase. He used a great deal of humour throughout the narration and, at times, sarcasm. At the end of the interview Robert disclosed he was retiring and was clear that the 'politics' of the organisation 'didn't interest him'.

Roberts's career path represents the 30-year period focused on in this study. He began his narrative by describing being 'at a loose end'. He qualified as a learning disability nurse in 1980, after initially starting teacher training and then deciding to do something different. He was at college prior to applying to do his learning disability nurse training and was guided by a tutor to have a 'look around' the local mental handicap hospital. After initially failing his final nursing exams, he qualified and was a staff nurse in a large long-stay hospital. With a view to working in a community setting, Robert went on to undertake his general nurse training. After some time working in acute adult nursing and, due to a change in his living arrangements, Robert went back to work within learning disability in 1984. He described this time as a time when he ended up back in learning disability nursing due to circumstance rather than choice when he says:

*So I pitched up here and went to the (names large acute hospital) and said 'give us a job', and they said 'well we haven't got any jobs but they have got some over in the mental handicap unit over the road', and so I walked across here and then the nursing officer said 'when can you start.*

Staying within the same organisation he joined in 1984, but working in a number of roles, Robert became responsible for two services and involved in a number of national initiatives; including one around accessing health and another as an expert advisor for the Valuing People (DH, 2001) support team. As part of Roberts's time in these roles, he was seconded out of his employing organisation to work in another. During his time away from his employing organisation, his role there changed so when he returned from secondment large parts of his job had changed.

At the time of interview, Robert was preparing for retirement but he described this as being a time of uncertainty about what retirement might look like for him saying:

*I can't see in the fullness of time that the soapbox attitude that I've had is going to be removed so I suspect that somewhere along the line I will come back in to the world of learning disability, but I don't wish to work for my current organisation and I don't wish to particularly be party to the politics. And I think the thing that I've lacked for too long is actually any hands-on experience with people, which would be far more stimulating really, instead of just pushing the creative maths around the table, yes.*

Robert ended his interview with a quotation from a poem on his office wall reflecting upon uncertainty. He linked this to direction in learning disability nursing and used irony to make a link between 30 years of learning disability nursing history and 'still not knowing where we are going'. My feelings when we began the interview were that it was potentially going to be difficult, as I got the impression that Robert wasn't used to interviews where he needed to narrate a story, so suggested lines of questioning and asked if he was giving me the 'right kind' of information. He narrated the first part of the interview very quickly and chronologically, but when we had a break and I started prompting for Particular Incident Narratives (PINs) (Wengraf 2001), he seemed to relax a little and give more detail to his story. I drove home from the interview after writing up my field notes in the car, thinking that Robert was someone who had described a long career but who was clear that this was the end of that particular aspect of his working life.

## **Lorna**

I met Lorna at her workplace after an approximately 120-mile car journey. We settled for the interview in a small office and Lorna was friendly and open, talking about her career. Lorna qualified in 1981. She had wanted to be a nurse from around the age of 10 and, after leaving school at 17, did a pre-nursing course and a placement working in a residential school for children with epilepsy. After some time working in residential social work, Lorna was initially undecided about whether to do mental health or learning disability nursing. She applied to learning disability nursing in 1978. Once qualified, she worked as a staff nurse in a learning disability hospital setting but, having found that she was coming across health problems that she did not feel she had enough knowledge about, she decided to do her 'general' nurse

training. Prior to starting this course, she went abroad and used a range of skills, supporting families in rural settings. On Lorna's return to the UK, she undertook her 18-month general nurse training but, on completing the training, she returned to learning disability nursing and a community team. Two and a half years later, Lorna decided to work abroad again and went to Borneo as one of the first learning disability nurses employed by VSO to work abroad. In the early 1990s Lorna had returned to the UK and was working as a senior nurse in the south of the country. Family circumstances meant a move to the south west in 1995. After undertaking a public health degree in 2006, Lorna put forward a proposal to her local public health department and created her current role in public health. She saw this role as crucial to encouraging the inclusion agenda, but also recognised that many of the staff she works with may not see her as a learning disability nurse:

*I mean probably people in the office that I work with every day may not know I'm a nurse, they may or they may not.*

Lorna's role at the time of the interview was unique for a learning disability nurse, which she saw within her narrative as being part of her own determination to create this role and have an impact. She recalls her manager spurring her on to demonstrate why her role was needed. Lorna remembers her saying 'show me the value of what you can offer this team then we'll look at it'. Lorna suggests that 'it is having the people, the right people in the right place at the right time as well as the sort of guts to sort of keep bashing your head and going back for more'. Lorna also described the current work she was doing on a national group examining the sensitive area of premature deaths in people with learning disabilities. She spoke with a passion about the early findings and the difficulties of working with families affected.

The interview with Lorna was relaxed and she spoke with ease about her reasons for choosing learning disability nursing, her feelings around needing an additional nursing qualification, and spent a good deal of time focusing on her work overseas. There was an element of quiet pride in her descriptions of being the 'first' learning disability nurse in a couple of areas of her narrative, the work overseas, and in her role as public health specialist.

## Karen

Karen's interview took place in her workplace in a university setting. I knew Karen from national work in learning disability nursing and had met her a couple of times previously in meetings, so the introductions were around the research and the type of approach that would be used. Karen's desk included many mementos and artwork created by people with learning disabilities and her narrative also showed genuine warmth when discussing relationships with people with learning disabilities, and also a strength and confidence in her views around people with a learning disability:

*Even now I believe teach strongly about the context of personhood and the fact that there are too many people with a learning disability out there that aren't even aware that they're human beings and, you know, I believe very strongly in the philosophy of normalisation, but it's a load of bo\*\*\*\*\*s really if your person doesn't know that they're a human being and if they don't know that they're a human being then the people working with them don't know they're human beings and that's really important to me.*

In her narration, Karen focused on people with a learning disability and took this right back to when she was around 14, and, noticing injustice, as she said, she 'became fascinated about the lives these kids led and the injustice that was in their lives and had this crazy idea that I could address this through education'. Karen qualified as a learning disability nurse in 1982. Originally, Karen had wanted to be a teacher but she was discouraged at school. While doing some work experience in a special needs school whilst at school herself, she found that she had an interest in people with learning disabilities. Although discouraged by her school from applying, Karen undertook her learning disability nurse training; after starting as a cadet nurse due to her age. Karen qualified in 1982 and was rapidly promoted within the hospital she had trained in. In 1985, after a variety of roles within the hospital Karen, was asked to open a small group home, which she did. She described the challenges around this but also the rewards. Then, in 1987, she went into nurse education and has stayed there undertaking a variety of roles since.

The interview with Karen was focused around relationships with people with learning disabilities and her passion for equity and justice. She reflected upon her values and beliefs a number of times within the interview and narrated her story, based on these values and beliefs from the early days of choosing a career in learning disability



nursing through to the values Karen attempts to instill in students. Surrounding herself with mementos and artefacts, which represented her relationships and connection with people with learning disabilities, reinforced this for me throughout the interview.

## **Paula**

My interview with Paula took place in an office in her workplace, a large long-stay hospital. I had known Paula in a professional capacity for many years and, during her narrative, this led to assumed understanding of local issues. It was a relaxed interview as Paula told her story, and, even when we had to move location because someone else needed the room, the story flowed naturally and easily. Paula appeared reflective when discussing her initial experiences of learning disability prior to applying for her nurse training. She was aware of how her narrative at the time of the interview may be based on years of experience and, making sense of those experiences over 30 years previous, with hindsight. At one stage when discussing her friendship with a child with learning disabilities when she was young she said:

*It was still like a mix, when I think back actually it was quite.... in many ways ....I think it was probably quite advanced I suppose, ....I went to grammar school in 73 so I'm talking about the mid 70s, which is early on, and I guess there were a lot of things going on and perhaps I wouldn't register that they were having things done to them .....it felt and it still feels that we very much did things together and it still was very much that element of friends.*

Qualifying as a learning disability nurse in 1984, Paula had originally wanted to work with horses. Having a family friend who had a learning disability and, after doing some voluntary work with people with learning disabilities in a social environment, led Paula to feel that learning disability nursing might be for her. Starting her integrated course in 1981, Paula had decided quite early that learning disability nursing was her goal, but she also saw the integrated course (dual qualification in learning disability and mental health) as an opportunity to gain more than one qualification. After qualifying, Paula took up her first staff nurse post in the hospital where she trained. She worked on a range of wards until 1986, when she got her first community nurse post at sister/charge nurse level within the Trust's community learning disability team. Moving from a county to a city-based team in 1989; Paula gained further experience as a community nurse. In 1995, Paula moved into a

management post, managing community areas and, although the nature of her role has changed a number of times in terms of whom and, geographically, where she manages, Paula has stayed in this management role.

Interviewing Paula felt as if I was with a natural storyteller, her story flowed easily and she appeared to have no concerns with the interview technique. Like other participants, I had known previously in my local area there was an assumed knowledge of the local health provision and an expectation of shared understanding.

### **Matthew**

I met Matthew for the first time at the interview. He requested this be at his home where he was running his consultancy business. The house was not particularly easy to find and it was an interview I initially felt a little unease around as I was meeting in his home and it was someone I had not met previously. Matthew was very welcoming and offered me a drink and initial we chatted about the journey and I gave him some background on the research. Matthew then gave me some detail about his business before we started the interview. It was probably this business that encouraged the focus within his narrative on networking and those he termed 'the great and the good'. He linked his perception of these people with networking for him personally:

*There were a lot of the great and the good of that particular era that were.... you know, and for me it was a bit of a wow factor you know because these were the people you were hearing about... the movers and shakers that were doing all the stuff and they proved to be useful networks for me.*

Matthew qualified as a learning disability nurse in 1985, as a mature student. He had already been to Drama College but did not finish the course for financial reasons. Through a friend, he had the opportunity to do some work with people with learning disabilities who attended a play scheme. This positive experience encouraged Matthew to think about a career working with people with learning disabilities. After enquiring about the social work route and finding, you had to be sponsored by an employer, Matthew then found out about training as a learning disability nurse and he started his training in 1981. After qualifying, he went to work in a day service but also undertook a psychology course and then, some 18 months later, became a

charge nurse in a unit for children and young people. He became a social services manager of a specialist unit and then moved onto setting up and managing a day service. In the late 1980s, Matthew went to work for the RNIB as a trainer; eventually becoming a research and training and development officer by 2005. In 2007, Matthew set up his own training and consultancy business and at the time of interview was working with a number of agencies.

The interview was, after an initial hesitant start, relaxed and comfortable. Matthew told his story in a linear way with emphasis on the professionals he had met along the way and the importance of certain people in his professional career. He also focused on two particular people with learning disabilities who had been key to him developing teaching and learning materials and his assessment skills. Matthew was another participant who focused heavily in his narrative on relationships, for him these were both professional networking relationships and those with people with learning disabilities.

### **Annette**

I met Annette some 25 years prior to the interview, as we had trained as nurses at the same time and in the same hospital. We had remained in contact for the years following as friends but discussed little about our professional lives, which had taken two very different pathways. This interview appeared challenging initially to Annette, perhaps due to our long-term friendship. Following the interview Annette also commented that the technique of me listening to her narrative without interruption or question felt unusual and a technique she was not familiar with. She reported that she 'didn't know what to say'. In the second phase, where I used specific questions to highlight and expand parts of her narrative (PINs), she was much more comfortable and her story flowed more naturally with fewer pauses and hesitations.

Annette qualified in 1987, after doing a pre-nursing course. Initially she had wanted to work in a hospital setting but more on the clerical side. In the early part of her interview she said:

*Well when I was at school I always thought I would like to work in a hospital setting but definitely not as a general nurse, that didn't interest me at all so I looked at sort of x ray department, physiotherapy, erm clerical side of things.*

Even though Annette had felt nursing was not for her, she decided that a pre-nursing course at college might give her some wider opportunities. During her pre nursing course, however, she undertook a placement in a special school and then went on to do six months' casual work in a local authority residential setting, working with people with learning disabilities. She describes this time on her pre nursing course as a time when she made a decision that this was the area in which she would like to work:

*I worked at a special school and that's when I first really learnt about people with disabilities. I really, really enjoyed it and decided that was the area I wanted to work in.*

After qualifying, Annette stayed in the hospital she had trained in and was promoted through to Ward Sister. However, after getting married, the 50-mile round trip between home and work became more difficult and she looked closer to home. She secured a position in a day centre setting, working with people with learning disabilities. After around 18 months, she went to work in a residential unit run by social services; as an assistant officer in charge and, at the time of interview, is there some 16 years later as a senior care manager.

Annette's interview was one of the early interviews I undertook and, whilst I felt comfortable in her presence, the interview situation felt a little awkward for both of us. However, there were many aspects of her narrative that we had never talked about as friends and, whilst I knew her most recent career history, I was surprised that many of the feelings she described we had never discussed as friends. This interview caused me to reflect a great deal, on how little we talked about our work and our feelings and how the narrative interview had enabled that to be told. Overall, Annette's narrative suggested that working with people with learning disabilities was more important to her than her title as a nurse or status.

## David

David's interview took place in his workplace around a 60-mile drive from my base. I had met David briefly before in a national learning disability nursing meeting. He was very effusive and happy to tell his story, using humour throughout and a story-telling approach that identified characters and brought those characters to light with changes in his voice, inflection, accent, and levels of humour. This aspect of his narrative meant that the linear approach to his career and experience was a minor part of a story, which largely focused on the experiences with people during that career. At one point towards the end of the interview, he questions whether he has had a similar career to other participants:

*I don't know whether this is a typical career that I've explained to you but you know it's kind of... I've had a reasonable rapid rise to fame... I've been a senior person for some time, I've been lucky in the fact that I've been able to influence things because I've been a budget holder, or I've been sitting on management teams.*

David's interview was the longest of the participants', taking more than 90 minutes. He needed very little nonverbal prompting for him to narrate his story and, during the second phase, used the opportunity for further in-depth narrative to its fullest. David qualified in learning disability nursing in 1987. He had been taking a year out after A-levels and, through a friend, became involved in voluntary work in a long-stay hospital. After a time, this turned into part-time work, then full time, and then, after working alongside nurses and feeling, he could also make a difference, he applied for his nurse training. At the end of his training, David became a staff nurse on the ward where he had originally volunteered. After gaining promotion and a move to another unit within the hospital, David became the acting charge nurse. When a post of resettlement officer became vacant, David applied and secured this position, again within the same hospital. As people started to be resettled into the community, David got a post managing a group of small homes out in the community. The numbers of homes David was responsible for grew and grew. After some time, David took a six-month post within the trust; writing policy and doing some 'business plan work'. After this period, David went to manage an assessment and treatment unit for around 18 months, still within the same trust. Having decided he liked this area of work, David then moved to another area of the country and worked for a charity, in a

specialist hospital setting, with people with extreme challenging behaviour. When David's partner moved to another area of the country David also moved and secured his current position of modern matron.

At the end of the interview on the drive home, I stopped briefly to write up my field notes and reflect. The impression I had of David and his story was one full of enthusiasm and humour that largely came from the way he told his story rather than the progression of his career. There were challenges facing David in his career that were very similar to a participant I had interviewed earlier that week (Robert), but it was the telling of the narrative, the choice of emphasis, the use of humour, and the focus on the positive aspects of this experience that made this interview very different.

### **Jane**

I met Jane for her interview at my home after we struggled to find a mutually acceptable location. The interview with Jane was relaxed and she said she felt comfortable. We sat at my dining room table and I had offered Jane a drink to help her to feel at ease.

Jane qualified as a learning disability nurse in 1989. She had undertaken a health and social care course and been placed for work experience in a special needs school. There, she realised that she would like a career in caring and so the careers officer pointed her in the direction of nurse training. Jane describes her time starting out as a student as a positive time in her life:

*So I embarked on this three years' training, that I didn't really have a clue what I was really going in to, I suppose I didn't know much about institutions, I didn't know much about the care that was provided at the time, but I saw it as a positive thing, a positive time in my life.*

This positive time was also linked in her narrative to leaving home and moving away from family circumstances that she had described as difficult. Jane described some difficult times during her training when she was challenged by what she saw and questioned whether this was the career for her. After qualifying, Jane stayed within the hospital environment, working initially as a D grade (Whitley grading structure)

and then, within eight months, an E grade (Whitley grading structure); applying for deputy sister post some two years later. In early 1999, Jane moved from within the residential services in the hospital to a community-type job in outreach services, as a G grade. However, she was unhappy in this role, there were some challenges with staff and when, in the summer of 1999, a post had become available in the community nurses team she joined them. Jane has worked there ever since.

I had known Jane professionally for a number of years. Jane was very relaxed telling her story, and told a linear story starting from when she left school. She described her home situation but also seeing embarking on her nurse training as an adventure. Jane's narrative had a balance of descriptions of what she was describing as some very difficult times for her to examples of her work with people.

Although Jane approached the narrative with a relaxed approach, around two weeks after the interview had taken place I spoke to Jane unrelated to the research project and she said she had been left with some challenging thoughts following the interview. These particularly related to reflecting upon her family situation and some of the reasons she had given in her story about leaving home. We discussed this for a while, as I wanted to be sure she had the opportunity to share how she was feeling.

## **Martin**

I met Martin for the first time during his interview, which took place in my office on the university campus. He had travelled to Leicester from another county and took a little time to appear comfortable. I asked about his journey in an attempt to build rapport and, although he had suggested meeting on campus, he did say it was the first time he had been back to the university for more than 20 years. Once he started to tell his story, Martin told it easily.

Martin qualified as an enrolled nurse in 1989 and then as a registered nurse in 1991. Prior to this, during a period of unemployment after a career in the army, Martin was undertaking some voluntary work with a charity working with elderly people. A colleague who was an ex nurse, formerly working with people with learning disabilities, had suggested to him that he had the qualities of a good learning

disability nurse. He described this as a 'route to employment' rather than a considered vocation. As he did not have the entry criteria for a registered nurse programme, Martin undertook his enrolled nurse training, qualified and went to work in a residential setting. He was then supported by the trust to undertake his registered nurse training but, with no job at the end of it, he moved to a challenging behaviour assessment unit in another area in around 1993. In this role he was also involved in the setting up of a new home and the move of some people from a larger unit to a new smaller facility. He moved from this post to work on in a community-based behavioural support team, initially as an E and then as an F grade, until 2000. That year, Martin became a full-time carer for his disabled son who had been born in 1997, and left nursing completely. He spoke in his narrative about how 'burnt out' he and his wife were trying to balance jobs as nurses and come home and care for their son. Following divorce in early 2007, Martin went back into nursing; into a forensic residential setting, working with people with challenging behaviours and criminal backgrounds. Martin describes a change in his attitude since returning to nursing where he feels he has more work-life balance:

*I'm not blasé and people are all important to me, but that's the way I see things, I want to at half past three or whatever quarter past three I want to walk out the door' and isn't at all focussed on promotion 'hence I'm a band 5, even though opportunities have come to I am frankly not interested.*

Martin took a while within the interview to appear comfortable, but once he did his narrative focused on the changes in his life outside of work and the impact of these on how he approached his work. His son who has a disability, his struggle with the balance between paid and unpaid care, his divorce, and his current position in work, were all described in a way that gave the overall impression of 'struggle'.

## **Quinn**

I had never met Quinn prior to the interview, which was some 130 miles away from my base, in his office. He was very welcoming and focused largely on his 'professional story', choosing not to draw in too much of his personal life. Quinn qualified as a learning disability nurse in 1992, after arriving in England from Ireland in 1989 to take a care assistant job in the south of England. Having close family members who were nurses, Quinn had initially wanted to be a general nurse but



admission to nurse training was difficult in Ireland at the time. Quinn speaks about this very early on in his narrative:

*It was very difficult to get nurse training in Ireland when I'd left school and I had worked in the civil service for a few years, given up all hopes of being able to do my nurse training, and I saw an advertisement in an Irish newspaper where a Trust in the south of England was advertising for care assistants at that time to work with people with learning disabilities and I thought, if I can apply and get my nose in here, it may be a route in to eventually doing general nurse training.*

Five months after arriving in England, Quinn started his learning disability nurse training, still with a view to undertaking general nursing afterwards. After qualifying in 1992, he secured a role as a deputy manager in a behavioural unit. Two years later, he was seconded to the local learning disability community nursing team and undertook specialist post-registration training in this area. After some time working in a community team arrangement, he was approached by a charitable organisation to manage their residential services and saw this as an exciting challenge. However, after two and a half years, he 'missed the buzz' of the community teams and returned to work within these services. He has been lead nurse in a community team for the past five years. At the end of the interview Quinn also talked with some uncertainty about the future:

*We're currently employed by this trust, you probably don't want the name of it for our conversation, and we will remain employed by this trust until the 31<sup>st</sup> July next week, when from the 1<sup>st</sup> August we will become a separate provider service and we will be a social enterprise.*

At the end of the interview with Quinn, I took some time before my long journey back to write up field notes and reflect on our conversation. Quinn was easy to listen to and became more so as the interview progressed. As I pushed for Particular Incident Narratives (PINs) in the second phase of the interview, he became more detailed with his story. He presented as someone who focused on the rights of people with learning disabilities and their individual needs as he recalled very early on in his experiences trying to ensure needs were met. His memories of caring for people in long-stay hospital environments were described with a focus on his feelings about the people he was working with and the care being given.

As he described later elements of his career, he skipped back to his early career to 'fill in gaps' he had missed. I felt that, throughout the interview, he was not only piecing together the story for me, but also for himself.

## **Dean**

Dean's interview took place in his office at a Trust location. His secretary collected me from reception and this was the first clue about Dean's role, as few learning disability nurses I had met had their own secretary. I had not met Dean prior to the interview but his narrative stood out from all of the other participants in that he focused very specifically on his career pathway and, unlike the other participants, did not talk about relationships with people with learning disabilities at all.

In the second phase of the interview, I probed for further narrative around some aspects of his story that seemed slightly more uncomfortable for him to discuss. I was aware that I needed to be sensitive here to the fact that I had not met Dean before. Dean qualified as a learning disability nurse in 1996 but, prior to undertaking his training, had started a biology degree. Prior to starting his degree course, Dean took a part-time summer job working with people with learning disabilities and had a positive experience. Initially, he deferred the start of his university course and continued to do part-time work with people with learning disabilities in the hospital setting after he had started the course.

After a year, Dean left his university course and started doing 'bank work' within the Trust. He secured a short-term contract within day services and then applied for learning disability nursing; starting his training in 1993. After qualifying, Dean worked as a newly-qualified staff nurse in a six-month preceptorship post, and then applied for promotion and was successful. By 1999, Dean had been appointed as a charge nurse within the trust and had worked on a number of residential units. After undertaking a major project to develop a service, Dean moved out of the trust in 2003 to work for the local council in a non-nursing role. This was a project management post. In around 2005, Dean returned to work within health care in a joint post between a primary care trust and the local council. In 2006, an opportunity for a seven-month secondment meant that Dean gained experience working with the common assessment framework and, in 2007, he started working for his current

employer, a primary care trust; around commissioning, planning and health outcomes. The general feel for Dean's narrative was that he had experienced some very challenging times in his career which had led him to leave nursing altogether:

*There have been... certainly as I sort of progressed in my career, I think there have been one or two challenges that have knocked me and to the point where I wanted to leave nursing and did.*

The interview with Dean took place early in the round of 20 interviews, however, he remained an outlier in the focus of his narrative around role and career progression, in contrast to other participants who tended to focus around people and relationships.

## **Ryan**

I met Ryan for the first time during his interview with me for the project. I attempted to develop some rapport through asking some general questions before explaining the project and the interview technique. He told his story openly and easily. He used names of people throughout and his overall narrative suggested someone who liked to 'network' and to see the potential of those contacts for future career opportunities:

*I remember being approached by national leaders like (name) who was at the Department of Health at the time about it. I really realised what opportunities were on offer from there.*

Ryan qualified as a learning disability nurse in 1998. After undertaking some work experience in a workshop for people with learning disabilities, Ryan felt he would like to become an Occupational Therapist. He secured a post as an OT support worker, working with people with learning disabilities, whilst doing his A-levels, but realised he was not as motivated towards his A-levels as he had been initially. Working closely with two nurse managers in his support worker role, he was guided by them to think about learning disability nursing as a career option. At the age of 20 he gained a place to undertake his learning disability nurse training. After qualifying, Ryan went to work in a residential setting for six months, before securing a community nursing post. In 2001, Ryan undertook his community nursing degree seconded by another trust and, on completion, initially returned to his community nursing post, before moving into a community nursing/health facilitation post. In

2008, Ryan secured a post as a Practice Development Nurse in another trust that would support him in studying for an MSc:

*My clinical manager blocked any attempts to do the MSc I had been hankering for those five years. So when this job came up as a Practice Development Nurse for people with learning disabilities in East Kent Hospitals Trust, I grasped it with both hands.*

Generally Ryan's narrative appears to be one of some challenges to achieve what he wanted to achieve, but an important part of this has been the networks he has developed and some of the opportunities that these have opened up for him.

### **Julie**

I met Julie for the interview at her home, as she had said this was the most convenient location. Having known her in a professional context for some years, both she and I said we felt at ease with this. She found the technique of interviewing fairly difficult and was more at ease in phase two when I was probing for expansions on the narratives using questions.

Julie qualified as a learning disability nurse in 2002. At the age of 16, she worked as a health care support worker with the elderly and with people with visual impairment, and was interested in care work. It was when working in a college for people with learning disabilities that she decided to apply to undertake her nurse training. Julie did the entrance test, her training, and qualified in 2002. Post qualifying, she spent a couple of months working in a small group home in the local trust and then applied and secured a post in a national forensic secure hospital environment; within the women's directorate. This was over an hour's driving journey from home and she described this as being difficult. After around two years, and feeling the need to be nearer to home, Julie went to work in the Children and Adolescent Mental Health Services (CAMHS) team in the town in which she lived. With an interest in communication, Julie has been studying a speech therapy course and, at the time of interview, was working within CAMHS as a communication lead.

Generally there was an acknowledged theme of communication within the narrative 'communication, everything seems to point towards communication'. Julie not only

acknowledged this early within her narrative but also used this to shape her story, coming back to this within descriptions of her experiences:

*I've sort of homed in on my communication side of what I do, what I've always done, I suppose looking back now sort of you know, looking back retrospectively I can sort of look at when I worked at the Wycliffe when I worked for the Society for the Blind and I worked for RNIB Agency for a while, everything seems to point towards communication (laugh) and it all sort of ties in and I did my British sign language, you know my stage one, and just little things and then a couple of years ago I thought I really want would like to do my speech therapy. ...So I applied and got into University and basically I'm at the point now, where in the last year obviously I have been off but you know off for having children and I've sort of myself and a colleague at work, we're both very interested in communication and that side of things and we're very passionate about what we do and do a lot with scheduling and sort of signing and symbols and things have sort of developed... developing a pathway... an assessment pathway based on behavioural approaches and from the work that we've been doing our team has recognised what we do and have developed a Communication Lead post.*

Julie described a range of post-qualifying experiences, but the theme of communication was one which she used to 'anchor' her story throughout the interview.

On reflection, and when re-reading my field notes alongside the transcripts, Julie presented this communication focus throughout even when speaking about her non-working life. She had a clear view about this element of her as a person, part of her identity which was probably being reinforced by her experiences at the time of interview as she studied for her speech and language therapy course.

## Narisa

My interview with Narisa took place in a room within the Trust she was working in. It was the first time I had met her but she was open and friendly and told her story easily, sharing both professional and personal aspects of her narrative.

Narisa had worked in jobs other than health care until she was around 34 years of age. Then, after spending a prolonged period of time with her son in hospital, who subsequently died, she saw what the nurses did. After giving birth to a daughter and being at home with her until school age, she was inspired to start her training in adult nursing in 2001. She decided that learning disability nursing was for her during a short placement in the early part of her nurse training, working with people with learning disabilities. After an interview, Narisa was allowed to change branches and continue her nurse training as a learning disability nurse. Narisa acknowledges the role her family played in supporting her to undertake her nurse training but also her ex-husband and his family being a catalyst for change in her personal life:

*My mum was all for it as, like I say, my mum's obviously a social worker and follows a similar thought process as myself, no it was my ex, well he's now my ex-husband and his family, his father and mother, are of an older generation than my parents and they were, they thought, there was no point to people with learning disabilities and had indeed lots of different names for them, my husband had obviously been brought up in that arena and carried those views also, although tried to be quite liberal, couldn't and so he didn't see the point of it. Very offensive things going on, but I got rid of him when I qualified [laughs].*

After qualifying, Narisa went to work first in a long-stay challenging behaviour unit and then an independent sector brain injury unit, finally becoming ward manager in 2008. Wanting to get back to working with people with learning disabilities and having an interest in issues around accessing health care, Narisa applied for and secured a post as an Acute Liaison Nurse and has been working in that environment since. At the end of the interview, Narisa said it had been 'cathartic' and she had felt 'counselled', suggesting that the narrative had been a story she was waiting to tell but also the technique had allowed her the opportunity to share the aspects of her story she chose to.

## **Debbie**

I had met Debbie some years prior to her interview when she was a student, but had had no contact since then. We met for the interview in my office on the university campus and she seemed very comfortable telling her 'story'. Debbie started her learning disability nurse training in 2003. At the time of the interview, she was aged 25 and working as a Health Care Facilitator within the local NHS Primary Care Trust. She had worked, at the age of 15, in a private residential home for people with learning disabilities. She had originally wanted to train as an adult nurse (general nurse) but had been encouraged to apply for learning disability nursing by her employers in her part-time job. A year into her training, she changed branches to adult nursing but didn't enjoy this and returned to learning disability nursing to complete her training. On qualification, Debbie took the offer of a fixed-term contract with the local NHS Trust, working in residential care. The fixed-term contract was described as unsettling: 'it's uncertainty about what your role is going to be',

At the end of this fixed term, she took up a post as deputy manager in the home where she had worked as a 15-year-old and where she had continued to maintain a relationship with staff and residents throughout her nurse training. In around 2008 she became a Health Care Facilitator in the Midlands; but this required a long commute to work. Around nine months later, she secured a position with the local authority outside of nursing, working with a review team. At the end of this contract, in 2009, Debbie went to work in a local children's hospice. This experience confirmed Debbie's wish to work with adults with a learning disability so, when she saw a post as Health Facilitator in her home city, she applied and has been working in this role since. Debbie's narrative was largely focused on relationships with people with learning disabilities and the importance of these for her. At one stage in the interview she became visibly upset when speaking about a person she had worked with who died. There was great emphasis on the role of people with a learning disability within her narrative, those who had shaped her decision making around her career choices. The other key feature was around the attempt to secure permanent rather than fixed-term positions to give herself the stability within roles.

## Angela

I had met Angela prior to the interview when she was a student nurse but had not seen her for more than two years before the interview. We met in my office on the university campus and Angela appeared relaxed and comfortable during the interview. Initially, in phase one of the interview, she seemed to omit aspects of the narrative she thought I knew, however, we were able to explore this further in phase two. Angela qualified as a learning disability nurse in 2008. Originally, Angela had started her nurse training in mental health, after spending some time as a dental nurse prior to this. Having undertaken an enjoyable placement in learning disability and being dissatisfied with her choice of mental health, Angela left the course, had children, worked outside of the NHS and reapplied some five years later to undertake her learning disability training. She described this time in her career as difficult, with some uncertainty about whether she would be taken back onto the nursing programme after a break:

*I wasn't really doing anything at that point so I sort of started looking at courses and looking at the nursing again and looking at the learning disability nursing part of it and that's when I decided I needed to go back and see if they would have me back, really, because obviously I'd left once so I wasn't really too sure on whether I'd be accepted back, but I was.*

After qualifying, Angela went into a staff nurse post within the private sector; working with people with challenging behaviour. After a year, she was promoted within the organisation to senior staff nurse and, in 2010, was promoted again to Developmental Charge Nurse.

Angela's interview took place just over two years after qualifying as a learning disability nurse and her narrative reflected this in both length and content. She appeared to be reflecting throughout the last part of the narrative on her current position and whether she would continue in that role. This focus on the potential future rather than the past gave me the impression that she may have been ready to move on from the role she was in.



## Jenny

Jenny's interview took place in my office on the University campus. We had met before when Jenny was a student nurse. She said at the beginning of the meeting that she was very nervous, so we spent a little time chatting to ease the anxiety. She told her story very quickly and succinctly in phase one but, as we moved into phase two and I was pushing for expansion of the narrative around particular incidents, she was much more relaxed and able to expand her narrative further.

Jenny qualified in 2008, applying to nursing after undertaking a health and social care qualification at college. It was during this course that Jenny had some experience working in a special needs nursery setting and decided that learning disability nursing was for her. Jenny started her nurse training in 2005 and continued working in various part-time positions with people with learning disabilities before and throughout her nurse training. During her training there was a point when she was overcome by the negativity around learning disability nursing and asked to swap to adult. This was not supported by the university, however, so she continued with her learning disability nurse training:

*Yes... my general placement I loved that and I did actually go and ask if I could swap to adult after I'd done that, which I'm glad I didn't, I mean that was like a day surgery so I got to go in and watch the surgery and stuff and that was really interesting and I do remember I really enjoyed that and it's only eight days.*

She acknowledged at this stage the 'support' of a lecturer on her nursing course who advised against changing to adult nursing:

*It was a bit silly to sort of say that's it, I want to swap now. (Lecturer name) was very good at saying no that's it, which is good because you know I think a couple of weeks later I was like no, because I wouldn't have enjoyed it I don't think.*

Towards the end of Jenny's nurse training, she had a placement in a supported living environment within the private sector and secured a post there as team leader when she qualified. After eight weeks, Jenny was asked to be a temporary service manager and this post then became permanent. At the time of the interview, Jenny manages a number of supported living services within a private sector organisation.

Jenny's narrative was focused on a chronological order of experiences with little initial focus on feelings and beliefs or values. This may have been because she was relatively inexperienced as a qualified nurse with only two years of post-qualifying experience, but there may also have been an effect from knowing me as the interviewer. The second phase of the interview offered the opportunity to draw out thoughts and feelings and in this part of the narrative Jenny opens up more and describes some of her feelings around particular aspects of her narrative.

## **Wendy**

Meeting Wendy for the first time was with a little nervous anticipation, as we had been emailing each other in the weeks prior to the interview as Wendy had said she would like to be part of the study but had not been working for a while as she had a diagnosis of a terminal illness. We discussed via email whether she would like to be part of the study and I explained that she could withdraw at any point, and would see the transcript prior to data analysis. We also discussed the nature of the learning disability nursing community and some of the difficulties in maintaining anonymity. Wendy was keen to be involved, but I remained nervous when meeting her.

Wendy chose the meeting place close to where she lived; a quiet pub, and we found a corner to sit undisturbed. She was friendly, open and used humour throughout her telling of her narrative. She had lived this story. It was me hearing it for the first time. Wendy started her nurse training in 2009 after working in catering for some years. She had some experience of illness, both physical and mental, in her close family and decided she would like to be a nurse. At the time of the interview, Wendy had retired from nursing on ill-health grounds after being diagnosed with terminal cancer. She had had a difficult period during her training and on the first day of her new job post-qualifying collapsed, was admitted to hospital and was later diagnosed with cancer.

Her journey into learning disability nursing had been like many other participants, a journey first into nursing and then, after working with people with learning disabilities, a choice to train as a learning disability nurse. Wendy had also been determined to 'prove her father wrong' as he had told her she would never become a nurse. At the time of the interview, she described a difficult relationship with her father, with little or

no contact for a number of years. Wendy also separated from her husband during the period of nurse training and was then managing her nurse training whilst raising her children. There were many challenging times for Wendy during this time, including serious illness, her marriage breakdown, and managing teenage children on her own. She also describes the negativity of others towards a career in nursing, more specifically learning disability nursing, starting with her father when she was around 16, and then with those working in care services, suggesting that learning disability nursing was 'going nowhere'. Wendy's story was, however, one of determination and she describes this as 'almost killing her' as she ignored the physical health problems she had in order to continue with her training. A key memory of the interview for me was when Wendy talked about 'giving up' nursing due to her illness:

*Then it proper sunk in and I did more and more research and realised that I had no option I had to get a surgeon to operate because I was dying, and I couldn't breathe. I was getting really laboured breathing, was in and out of hospital because me stoma weren't working and stuff like that. It was just a nightmare and was liaising with work, trying to sort of be upbeat, they were like oh .. had me in and I think that was the first time I cried and then I realised I was totally obsessed with this job (laughing) because I never cried when I found out I'd got cancer but when the thought that when they said look you've really probably need to just concentrate on getting well and your contract finishes in March, so you seriously you know we're 100% behind you if you want to retire on ill health.....And our advice to you is to enjoy what time you've got with your family, I was like you have got to be joking (laughing) you've got to be joking, and it's the only time I cried, just the thought that I couldn't go back to work.*

The narrative around becoming a nurse ends for Wendy upon qualification and retirement on ill-health grounds some months later. At the time of interview, Wendy was still on the nursing register, had had major surgery and was hopeful that she would be able to go back to work sometime.

My reflections upon this interview were, at the time and when re-reading the field notes and transcripts, a mixture of emotions. Wendy had described risking her health and potentially her life to be a nurse. She had also reflected at the end of the interview that this may all have been to 'prove herself,' as her drive to actually practice had waned once she had achieved her qualification. The focus of her

narrative was on the personal aspects of her story; divorce, bringing up teenagers, and ill health could have created a very sad and potentially negative narrative, but Wendy told this with humour and positivity.

Postscript note: Wendy had major life-saving surgery and treatment and is now (23/3/16) five years cancer free and working occasionally as a carer.

## **Chapter 5: Becoming a learning disability nurse**

### **5.1 Introduction**

This chapter presents participants' discourses around becoming a learning disability nurse, the journey from thinking about becoming a nurse through to training as a learning disability nurse up to qualification, a superordinate theme across the narratives. Learning disability nurses in this study discussed their memories of the role family, friends and significant others played in influencing decisions to choose learning disability nursing as a career. In addition to family members and friends influencing choices for some participant's work experience, working with people with learning disabilities was also a major factor in career choice. For other participants, changing life circumstance was the key aspect of their story and the findings suggest that a complex multiplicity of influences were outlined in the narratives. Participants also recalled questioning the decision to train as a learning disability nurse as they faced challenges in their journey as a student nurse. The superordinate theme of 'becoming a learning disability nurse' includes sub themes including influencing factors, uncertainty and challenges. Fig.1 summarises the themes identified within these aspects of the narrative.

Fig.1: Becoming a learning disability nurse

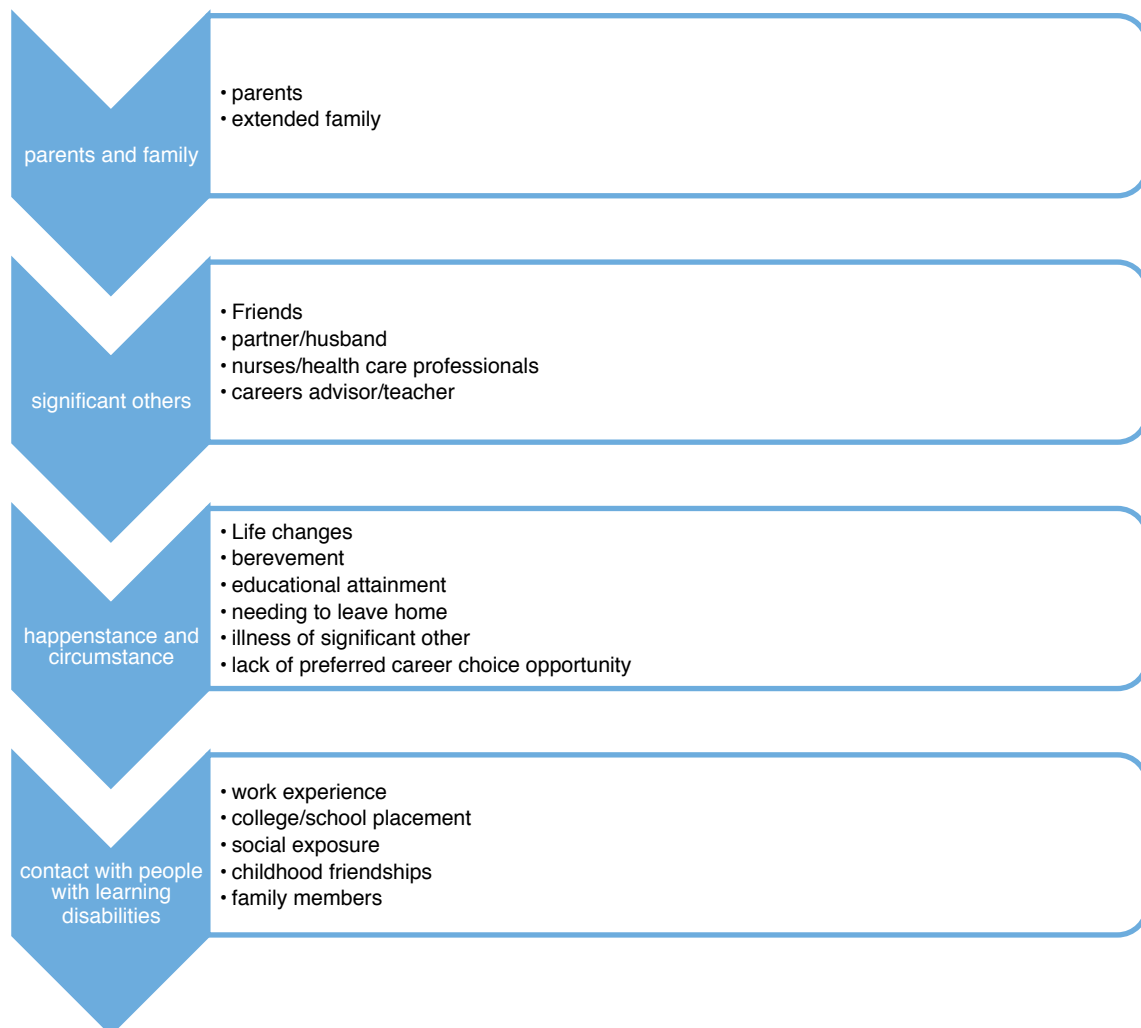


The chapter begins with participants' commentary on choosing nursing as a career, although, in the initial stages at least, this was not necessarily learning disability nursing.

## **5.2 Factors influencing choosing 'to become' a nurse**

Ten of the 20 participants in this study discussed extrinsic factors influential in their choice of career, similar to those identified in Owen and Standen's (2007) study. Although a limited body of research exists around the motivations and influencing factors in choosing learning disability nursing, Owen and Standen (2007) have identified at least some key influences; for example, parents and friends, work experience, previous positive experience of learning disability, and life changes. In keeping with the Owen & Standen's study, there were examples of each of these influencers from the participants in my study. The participants cited a variety of extrinsic factors including the influence of family and friends, timing within a life trajectory, major life events, and educational background. Fig 2 outlines the sub themes within this aspect of the narratives.

Fig.2 Influencing factors



Seventeen of the 20 participants in my study do not identify learning disability nursing as their initial career choice, with the decision to become a learning disability nurse often pre-empted by multiple factors, thus highlighting that decisions around career choice are multifaceted and complex.

### 5.2.1 Influences: Family and significant others

The limited but significant UK-based body of literature around the influences on career choices towards nursing suggests that family plays an important role in the decisions made around career choice (Neilson et al, 2012; Beck, 2000; Price, 2009; Williams et al, 1997; Larsen et al, 2003). One participant, Lorna, described her father as being a crucial influence on her choice to become a nurse, which was later

reinforced through work experience. The resultant effect as described by Lorna was to strengthen Lorna's motivation for nursing. When asked if she could remember when first thinking about learning disability nursing, Lorna recalls her father using nursing as an alternative suggestion to a career he didn't feel suitable for her.

*Yeah I can remember exactly because I was... for Christmas when I was 10 years old my dad bought me this book, 'I want to be a nurse' and I remember, I'd been saying I wanted to be an Air Stewardess an Air Hostess as it was then and that he was saying to me 'oh you know you're too big you can't be an air hostess they're all very glamorous and slim and I was a bit...' and so he bought me this book 'I want to be a nurse' and I remember looking at it and thinking 'yeah this looks really interesting' and I just had a real fascination with hospitals, particularly general hospitals actually at first. (Lorna)*

Lorna's account suggests that her father was key to her early thoughts about nursing. This reinforces the significance of key family members asserting common preconceptions about the nature of nursing to an impressionable young person, enabling them to influence long-term career decisions. In this case, Lorna's father reinforces an idea of who is and is not suitable for a certain profession. Lorna's narrative suggests that it was particularly hospitals she was interested in when exploring the idea of nursing as a career however, it is later in her story when she adds that work experience with people with learning disabilities further shaped this desire to be a nurse towards learning disability nursing. Socially constructed preconceptions of nursing (and of air crew) may have been part of Lorna's father's reasons for suggesting that Lorna become a nurse, and how Lorna remembers this some years later forms the narrative she presents, suggesting that this early message about her future career, amongst other influences, shaped her choice.

Another respondent, Debbie, also had very early childhood memories of a parent suggesting nursing as a career option, again reinforcing the power of family figures to influence career decisions at key life stages:

*Oh I don't know, it was my mum woke up one morning and she was like oh I've just had a dream that you were a nurse and I was like ooh that's not a bad idea, so I was probably about seven. (Debbie)*

Whilst Debbie remembers this as an influence early in childhood, this reinforces views around social identity and the influence of others on the perception of self (Anderson, 1993; Hemsley Brown and Foskett, 1999; Mooney et al., 2008; Goffman,



1978). Both Lorna and Debbie have early childhood memories of suggestions by parents that nursing may be a suitable career, however, as Lorna acknowledges, this would have been around general nursing rather than specifically learning disability nursing. Aspects of a developing personality may be seen as synonymous with traits you would expect to see in nursing, for example, being caring or patient, and these may therefore shape the view of others towards appropriate careers, especially for females.

For Wendy the negative message from her father 'I can remember me dad saying to me when I was 16 'you a nurse? You'll never be a nurse',' was a key part of her narrative. It took Wendy another decade or so of working in a variety of settings to start her nurse training, but she describes eventually seeing this as a way to prove herself even though a serious illness meant she didn't manage to practice as a nurse beyond qualification, when she recalls:

*And I'd.... you know... got it into my head that it was going to solve all my problems. It was gonna... gonna fulfil the dream that I was going to be a nurse that my dad had always said that I could never be.... I'd never be a nurse and I do believe that was one of the big things that was driving me because I'm not too worried about not being a nurse anymore. (Wendy)*

The influence of a parent or significant family member was also highlighted by Quinn, who didn't describe the words used by his mother but the fact that she was a nurse herself. He says:

*I can recall thinking about doing my nurse training when I was at school and my original interest was in general nursing, acute nursing and that was possibly because of my mum trained as a general nurse even though she didn't practice. (Quinn)*

Fourteen participants' narratives describe influencers in their lives who had encouraged them to think about nursing per se as a career choice. This was not always family or friends but, as might be expected, college tutors and teachers also played a role in the narratives of a number of participants. Angela describes the tutors on her college course as being a key influence:

*When I was at college I originally wanted to be a dental nurse, and all the tutors that were at college were all ex nurses, health visitors and that sort of thing, and they tried to put me off as much as possible from being a dental nurse, and to go into nursing. (Angela)*

Additionally, Robert was also guided by college tutors who directed him towards work in learning disability:

*Spent some time in a college and hadn't done very well, went to see a tutor and said I liked working with people, usual sort of stuff there, very naive and he said well why don't you go and have a look at that mentally handicapped hospital up the road, and I'm not really sure why I stayed or why, what attracted me other than I felt I needed actually to do something and to get some form of qualification, because that was all that I knew in my head that I'd been told. (Robert)*

Jane was also advised by a careers advisor and she says:

*So I went to see the careers officer as it was a really big college down in (names county), and he said what do you want to do and I said I haven't got a clue, but it's got something to do with caring. (Jane)*

The negative comments made by teachers about nursing were also highlighted by Karen in her narrative. She describes having made the decision to be a learning disability nurse and this being discouraged by her school, but supported by her mother:

*I was a grammar school girl and when the grammar school found out that I wanted to be a nurse for people with a mental handicap as it was called then they sent for my mother because grammar school girls were too clever to wipe bottoms and blow noses and you know I was wasting my education. I was eight O-levels and two A-levels sort of material at the time, erm, but not clever enough to be an English teacher cos I couldn't do Latin. And fortunately my mother stood up for me and said you go to work for a long time so you go to work to be happy, so if she wants to be a nurse she can be a nurse. (Karen)*

Angela, Robert, Jane and Karen all describe part of their story which relates to the influence of others outside of their family networks when making a decision around career choice when they were in college or school. There is often a lack of understanding of the role of the learning disability nurse amongst the general public, teachers and careers advisors (Owen & Standen, 2007), and studies of school and college age students highlight traditional views about nursing as a career (Whitehead

et al, 2007; Neilson & Lauder, 2008) suggesting that the early influencing views around nursing as a career choice are then reinforced later by the general perception of nurses working with acutely ill adults in hospital settings.

In addition to careers advisors and childhood influences, others influenced some participants later in their lives however; these influences are often described in the narratives as part of multiple influences. David's story of deciding on learning disability nursing as a career includes the influence of his then girlfriend, but also some aspects of convenience and seeing working with people with learning disability as 'dead easy':

*I took a year out and I was going to do some, just some odd jobs, some painting and decorating and the girl who I was going out with at the time was a healthcare assistant in a long-stay hospital, it had about 390 beds..... so I thought I'll do this and I'll just go voluntary, I just want to do two mornings a week, that's what'll do because she was saying look we really need people, you'll get trained and you can help do things like physiotherapy programmes, feeding programmes this sort of thing, well I thought well I could do that dead easy and it's only five or six hours and it's free transport to and from, you know and I'll be seeing the girl I'm going out with. (David)*

For David, the influence of his girlfriend, who he describes as encouraging him to work within a hospital environment with people with learning disabilities, coupled with his view of teaching as 'hard work', motivated him towards a career in learning disability nursing highlighting the multiple influencing factors on his eventual career choice as he articulates his story.

A number of participants in this study acknowledge through their narrative the influence of others at different points in their lives. This influence is often towards nursing more generally than specifically learning disability nursing. Arguably, once participants had taken steps to find out more about learning disability nursing, the desired effect was achieved in that the decision was made to 'become' learning disability nurses, albeit by a circuitous route. The influence of others remains part of the narrative of choosing to become a nurse and is consistent with a number of studies (Owen and Standen, 2007; Whitehead et al, 2007; Neilson and Lauder, 2008; O'Connor, 2015). Of particular note within this study are that only three of the participants describe those influencing them suggesting learning disability nursing,

however, a set of circumstances for each individual led to them eventually choosing this career route. The following sections focus on those factors.

### **5.2.2 Circumstance, happenstance and life changes**

For a number of participants, nursing had not been their original career choice; only four of the 20 participants describe their original intention as wanting to be a learning disability nurses. Teaching had been an initial choice for five participants. Karen, for example, had originally wanted to train as a teacher:

*Ok. I didn't want to be a nurse I wanted to be a school teacher and I wanted to teach English and was told I wasn't clever enough to be a teacher by someone who was really mean. (Karen)*

David, too, had initially seen teaching as a preferred career option:

*I was determined that I wanted to be a teacher. So I did my qualifications, my A-levels, with an eye to go to, in them days, Poly. (David)*

Many of the characteristics identified as related to teaching may also be held by learning disability nurses. Studies exploring the motivation towards careers in teaching include altruistic reasons, described by Kyriacou & Coulthard (2000) as 'seeing teaching as a socially worthwhile and important job, a desire to help children succeed, and a desire to help society improve' (p.117). For a variety of reasons, David's initial career choice was not fulfilled and nursing became a more achievable goal. He had originally wanted to become a teacher, however, the death of his father was described a key point in his life when he re-evaluated his choices:

*My father died when I was young and I suddenly had to grow up overnight and I then started really concentrating on what I wanted to do and I was determined that I wanted to be a teacher. (David)*

This aspect of narrative is commonplace in my study, the story of being 'at a loose end' and chance or happenstance providing an opportunity to open up new possibilities. David and Robert had both identified with having the qualities required to be a teacher. In both their situations, they used the opportunities given to them by the local long-stay hospitals to re-route their careers into learning disability nursing. Both of them describe difficulties with realising their initial career aspiration of

teaching, but finding an alternative in learning disability nursing. These opportunities may also have been linked to entry criteria for specific courses and levels of educational study; nursing at the time, as David and Robert describe, was at either certificate or diploma level, with entry educational attainment being lower than that of a teaching degree. Today, as nursing is an undergraduate degree programme in the UK, Robert and David, like others in the study, would not find an alternative lower entry course for nursing. Additionally, both David and Robert began their nurse training prior to the Community Care Act of 1990, whilst large long-stay hospitals were still the main residential option for those people with learning disabilities needing care. Policy change has had an impact on choices of careers in learning disability nursing. Prior to the early 1990s, when many people with learning disabilities who required care lived in large long-stay hospitals, there were clear career pathways within large NHS hospitals, with clearly defined roles for nurses. Other participants, like Tina, note that the local long-stay hospital was a large employer and, for young people like her who could not afford to go to college, they provided a qualification and future career structure:

*When I left School I'd got places at Art College but somebody in the village had just finished their training in Art College, couldn't get a job. (Tina)*

For Martin, following a career in the armed forces, he was offered voluntary work:

*I was unemployed, I came out the army and I was... because I was unemployed you had to do these voluntary action things where you had to go and do some voluntary work and I think I had a choice of digging holes or something or going and working for Age Concern, which I did. (Martin)*

These aspects of narrative suggest a discourse around learning disability nursing being something you did because it was the 'lesser of two evils'. Throughout the narratives within the study, those participants who discussed choosing learning disability as a secondary choice fell into two broad areas; those who suggested that they came into learning disability almost accidentally and those who started thinking about another career and made a conscious and proactive decision to train as a learning disability nurse.

For some, the secondary choice of learning disability nursing is not addressed specifically within their narrative but, for others like Narisa, this a focus point as they describe key transition points in their lives when nursing became a realistic option for them. Narisa describes the combination of the death of her young son, her experience as a parent in a hospital setting, and her family circumstances, as influences in her choice to consider nursing as a career:

*I actually thought about nursing as early as 93. My son had a syndrome which he unfortunately died of at 10 months, but I realised because I was in hospital basically with him for six months... so I was living hospital life every day and I saw the difference in people's approach to nursing and which was very broad and I realised that nursing wasn't just about giving medication it was it was a certain type of person that had to be a nurse and I think that's what drew me to be an adult nurse because I felt that I had some of the qualities that I'd seen in the good nurses and could certainly deal with some of the qualities that I felt I had in the bad nurses and so that's when I started to think about it and then obviously my son died and I then got pregnant with my daughter and then just time ran away with me so I didn't think to go back and start studying again. I was working at the tax office and then there were some changes at the tax office that led me to feel that I didn't actually want to be a part of it anymore, it was all being computer based and no customer contact if you like, so I thought if I don't do it now I never will, my daughter was at school full time and so back in 2000 I started to look at nurse training... (Narisa)*

Having identified nursing as a potential career option following her experiences with her son in hospital, she had considered the qualities she had to be a 'good nurse'. In addition to her perception of self, Narisa also describes the particular point in her life when a nursing career became an option, which, for her, was when her child had started full-time school. Both Narisa and Quinn's narrative are in keeping with other studies, suggesting that many choose nursing as a career later in life and after other careers (Price, 2009 ). Quinn in his narrative described wanting to be a nurse whilst working as a civil servant but being hindered by living in Ireland and a lack of training opportunities:

*It was very difficult to get into nurse training in Ireland when I'd left school and I had worked in the civil service for a few years, given up all hopes of being able to do my nurse training and I saw an advertisement in an Irish newspaper where a trust in the south of England was advertising for care assistants at that time to work with people with learning disabilities and I thought if I can apply and get my nose in here it may be a route in to eventually doing general nurse training. (Quinn)*

Majomi et al in their study describe the concept of 'punctuated equilibrium', a time for change and transition, and studies focusing on mid-life career change also acknowledge that there are particular times of transition and change (Hoffman, 2015). Whilst this may be read as a time of unconscious change, the participants in Majomi et al study were 'active in reformulating, moderating and transforming their roles' (Majomi et al, 2003). These findings demonstrate that many participants in this study entered learning disability nursing as mature students and are reflective of the findings of researchers like Keogh (2014), who suggests that, on average, MORE THAN a quarter of nursing students are mature students. When asked about being a mature student, Narisa also acknowledged that this was something within her family that was a pattern in the women:

*And both my mum and grandmother went back as mature students, my grandmother went back and was a nurse and my mother went to do social work, so I think it is kind of a pattern we sowed our wild oats when we were young and then went back later. (Narisa)*

Narisa's focus in this part of her narrative identified that she saw this as a normal pattern of working life and studying within her family circle. In common with other participants in the study, Narisa narrated change and transition into a different vocational area.

Matthew had been drawn to nursing after studying theatre studies and working with people with learning disabilities, using his drama/theatre skills on a voluntary basis. His then girlfriend had encouraged him to do voluntary work, and, although he considered training to be a social worker, the practicalities of achieving this due to the funding mechanisms seemed too difficult at this time:

*So during that discussion somebody from Bristol and I don't know who it was said 'how about learning disability nursing?' and to be honest I didn't know anything about learning disability nurses, didn't know they existed because at that time all the long-stay hospitals were you know out of the community, just didn't know about them particularly if you were sort of like an inner-city person. Anyway they said well there is a School of Nursing and they got details of the courses so I then applied to do learning disability nursing and the first part of the course was September 1981. (Matthew)*

In addition to noting points in life when decisions were made about career choices and the impact of this, there were also aspects of participants' stories that suggested

their views about learning disability nursing at the time, including their perceptions of learning disability nursing. These perceptions are explored in the next section.

### **5.2.3 Perceptions of nursing**

Nursing has a particular public image, as previously discussed in chapter two, often focused on nurses who work in hospitals, wear uniforms, care for those who are ill and are female. Whilst the participants in this study are narrating their story as qualified learning disability nurses (with insider knowledge of the true nature of nursing), at the time they were choosing their careers they were members of the general public with little insight into the role of the learning disability nurse. Matthew describes having little understanding of nursing at this time, particularly the broader role that nurses may take beyond caring for the sick:

*But nursing generally I don't think I appreciated that nursing had a role beyond you know working with sick people in acute settings so just... just... Discovering that there were learning disability nurses was an education in itself. (Matthew)*

The image of nursing more generally suffers from a lack of contemporary understanding of role in relation to health and well-being. These aspects of narrative in this study are reflective of studies that identify that the public hold particular stereotypical views about nursing. The role of the learning disability nurse is even less well understood by the public, and this too was reflected in narratives of participants:

*Went through the course sorry, and when it was coming to the end I thought what I am going to do coz I didn't really know what to do. So I went to see the careers officer as it was a really big college down in (names county), and he said what do you want to do and I said I haven't got a clue, but it's got something to do with caring. (Jane)*

And when Angela is describing when she first thought about coming into nursing after being put off dental nursing by her course tutors, she says:

*And, to be fair, I didn't really know that much about learning disability nursing at the time.' (Angela)*



Matthew, in his discussion with a friend about working with people with learning disabilities, recalls:

*So during that discussion somebody from Bristol, and I don't know who it was, said about learning disability nursing and to be honest I didn't know anything about learning disability nurses, didn't know they existed. (Matthew)*

For the men in the study there are further considerations around the gendered stereotypes of nursing as a career. Matthew described having quite stereotypical views around the appropriateness of nursing as a career choice for men:

*Do you know what? I thought nursing.... I thought what a sissy job (laughing) you know as a bloke it was quite a macho it was a very sexist view that I had towards nursing. I thought there's no way on earth that I'm going to be a nurse (laughs) and I hadn't even envisaged or understood that were things as male nurses... (Matthew)*

Five of the seven male participants in the study stated that friends had been a key influence in them becoming learning disability nurses however, all also then undertook work experience, perhaps to check this influence out. This is also picked up by O'Connor's 2015 study which suggested that the influence of family and role models were paramount for men in choosing nursing as a career but, in keeping with other studies (Boughn, 2001; Ierardi et al, 2010), the caring or vocational aspects of the career are 'played down'. For Matthew, his perceived image of nursing therefore did not match his self-concept, seeing nursing as being 'working with sick people' and specifically women's work, he describes the influence of a friend and meeting people with a learning disability which enabled him to challenge his preconceived notions of the identity of the nurse, enabling him to consider the role of the learning disability nurse. None of the seven male participants uses words like 'caring' when describing their choice of nursing as a career, suggesting the findings in this study are reflective of what others previously alluded to, which highlight the gendered nature of nursing work.

#### **5.2.4 Previous experiences of people with a learning disability**

Having experience of people with learning disabilities, either as family friends or in a working setting, was described as an influencing factor by 13 of the 20 participants, Paula and Dean had early childhood experience of relationships with people with

learning disabilities. Paula described growing up with a family friend who had learning disabilities:

*(name) was just my neighbour, my mate, my friend, but then obviously I realised there were lots of other people similar to (name). (Paula )*

Dean grew up alongside a cousin with learning disabilities of a similar age to himself:

*It was just a nice time, but unfortunately, as my parents moved away from (home town), we sort of not lost touch but the times when we would catch up would become less and less frequent. (Dean )*

Both Paula and Dean describe positive early childhood experience,s suggesting in their narratives that this had an impact on the way they viewed people with learning disabilities. For a further nine participants, their experiences with people with learning disabilities came from work, either paid or voluntary. It is clear that the memories of these experiences shaped their decision to want to work with people with learning disabilities as a career option. Already in this chapter we have heard about the experiences of Matthew and David in relation to experience of working with people with learning disabilities prior to starting their nurse education programmes, and also Debbie, who had been influenced in early childhood by a comment her mum had made, went on to undertake some part-time work, which happened to be with people with learning disabilities. This was to shape her career choice:

*When I was 15 that started working with people with learning disabilities and that was kind of just by fluke really, needing a part-time job knowing that I wanted to be a nurse but I always thought that I wanted to be a general nurse, so I got a job in a private residential care home that at the time had three people with learning disabilities in... and I applied to do nursing and I was going to do general nursing again and it was my boss at the time at the care home was like why are you applying to do general nursing, you know you seem like you fit in so well with learning disabilities and I kind of re gave it a bit of a re-think and I did I loved doing my part-time job, got on really really well and bonded well with the residents there, so I applied to do learning disability nursing, so then I started training in 2003. (Debbie)*

Debbie clearly remembers the influence of her manager in this part-time job, but also already felt she had the qualities of a good nurse and had 'bonded' with the people with learning disabilities who lived there. Debbie's discourse around how she came to choose learning disability nursing stresses the suitability of her choice, which

concurs with the views of others (her manager). This section of her narrative suggests a strong deliberate choice at this stage. Her story also continues with her taking an opportunity to swap fields of study within her nursing programme to adult nursing. This part of her story is picked up in section 4.3.1 but here it is important to note that, whilst she reports that her experience of working with people with learning disabilities influenced her choice, this was challenged at a later stage in her journey to becoming a nurse. Mary, like Debbie, did not have the original intention to become a learning disability nurse but it was work experience that changed her view:

*Right, well, initially I didn't think about being a learning disability nurse, I wanted to be an adult nurse and at school I did work experience in the school for children with learning disabilities and it was at that point that I changed my mind and applied to (names local hospital) as a cadet nurse. (Mary)*

David's story also had a focus on work experience as a key influence in him making the choice to become a learning disability nurse. David had worked as a volunteer and then a part-time nursing assistant in a large long-stay hospital. When asked what about his experience had led him into applying for learning disability nursing, David said:

*It was the voluntary work really because I thought that actually I did really quite enjoy it because I was working with quite vulnerable... quite disabled clients and we were... well it was quite innovative the stuff we did, I mean it was a real true multidisciplinary approach. (David)*

David was describing people with learning disabilities as vulnerable and needing care, and he also articulated the innovative approaches to care he had been involved in as part of this role, consolidating the suitability of his career choice but also suggesting he was engaged more than 'average' in 'quite innovative stuff'. Like Narisa in her narrative, David felt he could identify areas he considered good and bad practice:

*I remember looking at some of the staff nurses and the charge (nurse) and as I say I worked with some really really good charge nurses and I worked with a couple who... I was just appalled... You know I was not happy and I used to resist either getting moved to the wards or I never used to roster to do over time on there or whatever. (David)*

In addition to what are described here as the external factors influencing the decision to train as a learning disability nurse, there were also some perceptions of 'self' described within the narrative. How people saw themselves shaped by external influences and experiences were described in two particular ways: the discourse around personality and self and the altruistic discourse around wanting to 'make a difference'.

Many of the phrases used within the narratives highlight perception of self as the participant reflects back on their decision to train as a learning disability nurse. They build in the experiences that may have shaped this view of themselves, but outwardly articulate this through a number of phrases particularly around caring:

*I suppose I'd always had that sort of caring bit in me, I mean it had mainly been aimed towards animals at that time (laughed) there was that sort of caring side of me. (Paula)*

*I think it's something about caring, there's something about the caring, I'm the oldest of four children, I think... I think that is a significant issue... and then, when I was 12 my dad died and I think I then became a carer for three younger sisters and a brother or two sisters and a brother and my mum who became very depressed and sort of... I don't know the caring sort of role came out more for me then and I think that probably led me even more towards the caring professions whatever that might be. (Lorna)*

*My husband's parents died, one died suddenly and then the other one died of cancer and I did a lot of caring for him and it made me realise I wanted to do my nursing. (Wendy)*

Seeing oneself as a 'carer', or with the traits required to be a nurse, is based on both the messages we receive and the experiences we gain. The messages are reinforced (or not) through good and bad experiences. The experiences described here by Paula, Lorna and Wendy are not specific to learning disability nursing but are told as part of the narrative to highlight the caring nature of the individual and potentially, therefore, their suitability for nursing as a career.

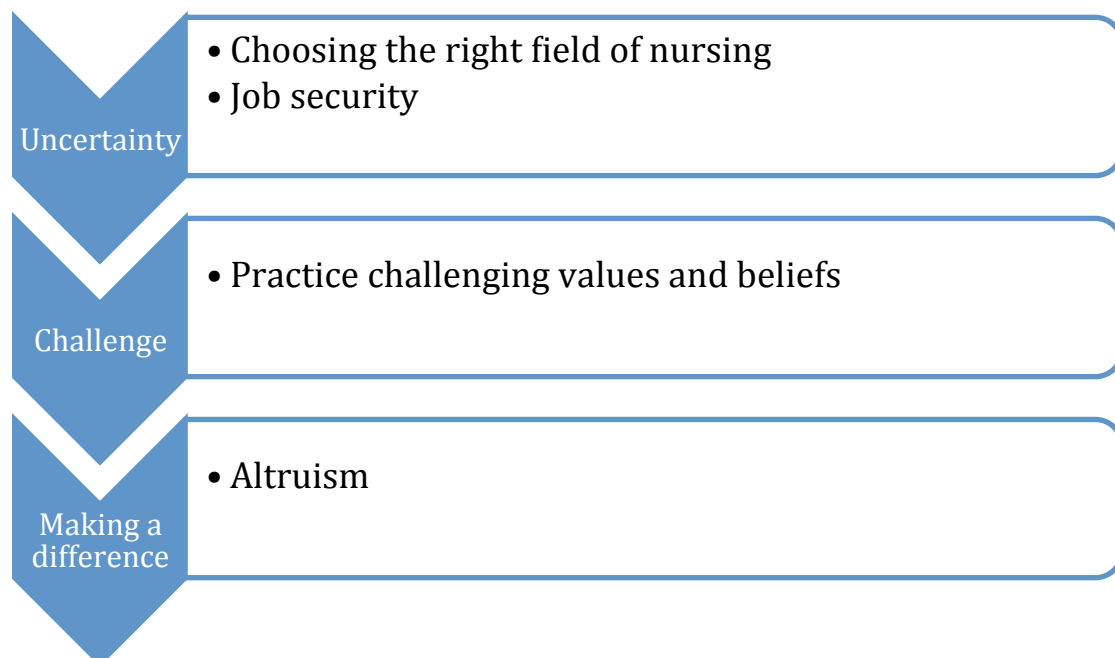
The findings within this section have focused on the themes around the decision to train as a learning disability nurse and the influences articulated around this decision including family, friends and peers, previous contact with people with learning

disabilities, and work experience. The following section will focus on the aspects of the narratives highlighting the experiences of the participants during their training.

### 5.3 Professional socialisation – learning the craft

Once the decision had been made to train as a learning disability nurse, the experiences during that training also shaped the identities of the participants in this study. For 14 of the participants, their narratives contained clear memories of their experiences during their nurse training. Dean, Angela, Debbie, Wendy and Narisa also gave an account of the concerns they had once they started their training as to whether they had chosen the right career option. The participants also narrated aspects of how they managed these challenges and their wishes to ‘make a difference’. Figure 3 represents the sub themes related to professional socialisation

Fig 3 Themes: Professional socialisation



### 5.3.1 Uncertainty

For 14 of the participants there were clear memories of their experiences during their nurse training. Within these narratives, there were accounts of the concerns they had once they started their training as to whether they had chosen the right career option. These doubts were often generated by comments from others.

Angela had started her nurse training in mental health and then taken a break from nursing. On her return, she had chosen learning disability but soon began to question her choice:

*I felt I'd made the right decision until I got here and everyone was saying 'ohh what are you doing the learning disabilities branch?' but I never actually had anybody from any of the other branches say anything to me about it but, I think being in such a vocal group at the time, who seemed to know everything that was going on, they put more of a more doubt in my mind than anybody else could have done really. Because when I was on my placements and some of the people that had been in the service for a long time would say some really negative things, but I just thought well that's just your opinion maybe you need to move on, maybe it would be better for the actual people if you moved on. But it was more the people in the group that, listening to them, because they did seem to know so much about everything that was happening in the learning disability and NHS sort of world and I didn't really know. (Angela)*

Prior to applying for her training, Debbie had been interested in adult nursing but was persuaded to apply for learning disability after the manager in her part-time job had suggested this might be more suited to her skills, however, a year into her training she became concerned about the negativity surrounding learning disability nursing:

*I did a year of learning disabilities but during placements and hearing people around the campus and stuff you didn't get very helpful comments on you know 'what are you doing learning disabilities for you won't get a job in learning disabilities?' and that de-motivates you so I changed over to do adult nursing and but never to think that I'd end up in adult nursing it was just a broaden my horizons a bit and at least I've got that as a back-up if there isn't any jobs in learning disability nursing. (Debbie)*

Debbie left learning disability nurse training for a while and moved to the adult nursing course. During this time, she had some experiences in an acute hospital setting; however, it was her connections with people with learning disabilities that

drew her back to learning disability nursing when an individual with learning disabilities she had previously cared for came into the acute hospital setting for treatment.

Debbie described the difficulties of wanting to undertake learning disability nurse training but being influenced by the negative views around her at this time. In describing her adult training, she focuses on the negative experience of visiting a resident (who we shall call M) she knew well from the residential home she had worked in as a 15- year-old who she felt wasn't receiving appropriate care in the acute hospital. In the second part of the interview, Debbie described this as one of the key influences in her decision to continue her training as a learning disability nurse:

*There's loads of stories I can remember when he (M) was in hospital that, that made me go back to learning disabilities. (Debbie)*

Debbie recalls sitting with M's mum whilst the consultant and nurses discussed what they perceived to be M's quality of life, and the 'Do Not Resuscitate' guidance based on their perceptions on these perceptions:

*I remember sitting with (M's) mum and she was dreading it because she was saying they're going to ask me what his resuscitation status is and I don't want to say it out loud and she was really worrying about it and so and she asked me to stay with her and then the consultant and two sisters on the ward came round they asked, they kind of presumed the do not resuscitate and they just like screwed their face up as she was like pondering over what it was going to be and was like well what quality of life has he got anyway and it's like, his life expectancy was 25 and by this time he was probably 28 and that was just through good care and knowing him so well, and it's like how can people just be so flippant with their comments and life, someone's life. (Debbie)*

Debbie describes spending a great deal of time advocating for M and his family in what was a conflict between her role as an adult nurse and someone who knew M and his family well. This internal conflict between the norms and routines of adult nursing and Debbie's values and beliefs led her to change back to learning disability nursing during her training:

*So kind of half way through my training I had that blip but there is absolutely no way that I would have changed that experience and doing that side of general nursing I did like it up until that resident went into hospital, I was always swayed to the people with learning disabilities that came in and they'd always kind of be mine that I would look after on the ward but, yeah when that happened I thought no you've got to go with what's rooted inside of you so changed back to learning disabilities and then carried on through and qualified. (Debbie)*

Debbie's narrative highlighted a conflict between her concerns about the future of learning disability nursing as a career and who she was as a nurse ('what's rooted inside'). In Debbie's story, her relationship with people with learning disabilities was crucial. Vaughan 1996, cited in Tschudin (2003), suggests that the relationships between nurse and patient are crucial and 'human contact seems to be the lynch-pin'. This connection between learning disability nurses and people with learning disabilities is a key feature of 19 of the participants' stories. This will be developed further in chapter six. Wendy, prior to her training, had considered mental health nursing but had enjoyed the work she was doing as a nursing assistant with people with learning disabilities so much that she decided to apply for LD and, although people questioned this choice, she stayed within LD nursing:

*I decided that I wanted to do LD and all the people that said to me 'you're mad why would you want to do that it's going nowhere?' and I still did it. (Wendy)*

Dean also had applied for another branch of nursing prior to changing to learning disability nursing, but still faced some negativity about his choice from others:

*I forgot to say I initially applied to be a mental health nurse on my training, and very quickly realised that I weren't because you know there was all that 'will there be LD nurses?', the advice was really go for your mental health then if LD is still around do your dual training, but to be honest after my first mental health placement as part of my common foundation I realised I didn't want to work in Mental Health, so I switched very quickly, my tutor helped me, she was an LD nurse so she facilitated that but the reaction that you got from some of the nurses and some of the midwives when you were doing your common foundation general placements was 'oh right learning disability nursing' you won't be interested in seeing this or doing that. (Dean)*

For Dean, Angela, Debbie, Wendy and Narisa, their training occurred at a time when the future of learning disability nursing was being openly questioned, long-stay hospitals were being built, and career structures for learning disability nurses in the



NHS seemed to be dissolving. Often the literature suggests movement out of learning disability nursing during the education programme and into adult nursing (Price, 2009, Owen & Standen, 2007). Narisa had started her training in adult but had moved to learning disability nursing after a short experience that had changed her views about the type of nursing she wanted to undertake. She describes how she felt when she found out she was accepted onto the learning disability training after some time on the adult branch of the course:

*I was elated because I had this knot in my stomach thinking I can't do adult nursing, I can't... this is what I want to do and you know if I've got to spend the next two years doing something I don't really want now I've had the taste of something I know I can do then it's going to be a waste of two years and training. (Narisa)*

Narisa had clearly felt she did not want to continue with adult nursing, her story suggests she did not feel a connection with the philosophy of care and was concerned about the lack of relationships she was able to develop with patients in the adult setting. The interiority discourse is apparent in the description of feeling 'elated' at having found her vocation, the discovery of self, however she knew that her choice would be unpopular with her family:

*So I have to admit it wasn't a popular decision with family, they well, I still joke now that I'm not a proper nurse. (Narisa)*

However, whilst both Narisa and Debbie made a choice to move into learning disability nursing, undertaking learning disability nurse training at this time did not provide the security for employment at the end of the training that was being seen in other branches of nursing. For Dean, Angela, Debbie, Wendy and Narisa, their training occurred at a time when the future of learning disability nursing was being openly questioned, long-stay hospitals were being phased out and career structures for LD nurses in the NHS seemed to be dissolving. There were many negative views around learning disability nurse education at this time, reinforced by a lack of policy guidance, difficulties in recruitment, and a reduction in commissions for learning disability nurse education nationally (Gates 2011).

### 5.3.2 Testing times

Howskins and Ewens (1999) suggest that professional socialisation is much more than learning the skills and knowledge specific to a particular role, but is also about the values and norms associated with that profession. These values and norms are time and culture specific, reflecting not only the profession's values but also those of wider society. Jane, Quinn, Dean, Martin, Robert and Annette all describe times during their nurse education programme when their values and beliefs were challenged working in environments they felt were difficult. The stories of these participants articulate working in difficult circumstances, demonstrating resilience, and a belief in self that they could change things. Jane and Robert describe the internalisation of some beliefs and values, whilst certain behaviours are avoided. Many narratives by learning disability nurses identify practices that they disagree with but feel powerless to change at that time:

*I knew it wasn't right, but I'd never met anybody, I didn't even know of the term mental handicap when I went there...(Robert)*

*You've made me remember how much joy I actually used to have when I cycled out of the gates at night, I didn't enjoy the company of the staff there and I can't say that people who were the cared for enjoyed the company of most of the people who were their carers. (Robert)*

*I just didn't feel that I could cope with the level of institutionalised care that was being given, I appreciated that to look after 30 women on one ward needed routines and systems, but how they were actually provided at that particular time at that ward I didn't agree with and I actually said to someone that I wanted to leave, and they told me to stop looking at the world through rose tinted glasses and get on with it. And at the time I was really upset but it was the best thing he could have said to me because it made me think, that right well, if you leave then these people will still be cared like this and you'd have left them to it, so I just got on with it then. (Jane)*

*I suppose I was just quite naive and you know, the way that people were cared for at that time wasn't what would be accepted now. And I knew that all those years ago like probably a lot of other people did, but there wasn't anything that I could do, I could only do my bit at that particular time and try and sort of vow that it wouldn't be the same if I had the opportunity to change. (Jane)*

Developing an identity as a learning disability nurse during their course had its challenges for both Robert and Jane, and this is highlighted in the stories of others. The distinctions they draw between themselves and their practice and that of others

suggesting a movement forward towards 'better times' and also identifying the potential for 'making a difference', as, even though the temptation was to withdraw from their training, there appeared to still be a connection with whom they perceived themselves to be and the need to continue. Jane particularly uses phrases like 'so I just got on with it' and 'I could only do my bit'. Jane undertook her nurse training at a time when long-stay hospital care was a key feature of NHS provision, there were clear roles for learning disability nurses within this environment, and jobs at the end of training were almost guaranteed. These may have been motivational factors in continuing during the difficult times she describes. Fisher & Byrne (2011) in their study suggest that professionals in learning disability are often driven to improve the satisfaction and rewards that stem from enhancing the 'wellbeing and quality of life for service users'. These 'rewards' are linked to the relational nature of emotions in that when we 'give something' of ourselves emotionally we also get something back. (Fisher & Byrne, 2011). However, it is also noted by Macintyre (2007) that the pursuit of transformation in practice is often not comfortable.

Challenges during nurse training did not just come from the practices identified when working with people with learning disabilities. For Narisa and Wendy, the change in their identity put pressure on their family situation. For both of these respondents their marriages broke down whilst undertaking their nurse training:

*I think it was just one of many things in that I had been a part time wife and mother and tea on the table when he got back, he came from a background that was you know, wives did that... you know they made jam, not that there's anything wrong with making jam, it was a more traditional parenting... and that's what I fell into and you know I'd had the baby, I'd got the husband, I was working part time and that was just something to keep me occupied and then suddenly that wasn't enough for me and he indulged me to go and do my training as he saw it and, of course, I changed, which happens to a lot of people I suppose. His tea was no longer on the table, I was working with people he couldn't understand why they... well to be honest why they existed in the first place so I couldn't have a conversation about what I'd done, my achievements or how I felt... (Narisa)*

Narisa acknowledged that she changed during her nurse training and that some of the values and opinions of her then husband were no longer shared. She describes changing her behaviour at home as well as holding different views about the people in her care. Wendy at the time of the interview had retired from nursing after a

serious illness, getting to the end of her training, qualifying, but on her first day falling ill. She acknowledges that her determination to become a nurse cost her both emotionally and physically:

*I've got a hell of a lot of guilt but that I ignored everything that was happening to me physically, completely ignored it, continued to ignore it, even when I knew there was something terribly wrong, and I nearly died for it. Because I was just so determined that nobody was going to stop me from being a qualified nurse, no matter what. (Wendy)*

In describing how her role working with people with learning disabilities changed how she approached her home life, Wendy said:

*It intensifies your relationship with each other so there was, they were my family. I'd replaced all that I got at home, I got at work. You know... you know being needed, being part of a team, being relied on and all that so you get everything being an LD nurse and so for me all me buttons were getting pressed at work and so I'd go home and I was just ooooooff... there was just nothing, there was nothing going on at home that made me want to be there. (Wendy)*

Wendy had acknowledged the determination she had to complete her nurse training and the effect that this may have had on her relationships and her health. Discourses of determination appear to be a feature of a number of the participants' narratives around their nurse training, but, particularly for Narisa and Wendy, this language of interiority tells a story of sacrifice for their vocation, a sacrifice of relationships and of health. Self-sacrifice is apparent in the studies around altruism (Carter 2014) and in early accounts of nursing as a vocation (Hallam 2002), however, the stories of Wendy and Narisa were told as part of the challenge of becoming a learning disability nurse and the way in which undertaking this type of training not only changes the way in which you work but also the way you view those around you:

*There was nothing going on at home that made me want to be there. (Wendy)*

*So I couldn't have a conversation about what I'd done, my achievements or how I felt... (Narisa)*

### 5.3.3 Making a difference

Whilst the findings based on these participant narratives suggest difficult decisions around career choice, negative attitudes from others around that career choice and difficulties in maintaining values and beliefs whilst working in difficult situations within the narrative of the majority of the participants of my study is a specific reference to the notion of making a difference. Embedded in altruism, this is highlighted in the literature around identities of nursing and professional socialisation (Owen & Standen, 2007; Johnson et al, 2007; Price, 2008; Fisher & Byrne, 2011). Sixteen participants in my study specifically identified 'making a difference' or other altruistic comments as part of their motivation for being a learning disability nurse:

*Making their lives better I think, changing things... Because it's changing, it's getting better. (Jenny)*

*My job satisfaction is from coming away that day and knowing that I've made that person happy for however or maybe their life worthwhile really and brightened their day up. (Julie)*

*It makes you feel like you have actually done something. (Angela)*

*I knew that I could make a difference to people's lives you know. (Matthew)*

*I thought I could make a difference and even if it's just to a few people. (David)*

This focus on 'caring for' or 'helping others' is a feature of the constructed identity of nursing that has existed for decades and forms many of the definitions around nursing (Kramer, 1964: 1974; Eron, 1955; Davis, 1975; Fealy, 2004; Johnson et al, 2007). Perceiving oneself as someone who can 'make a difference' or 'help others' can enhance the self-esteem of those who already feel these characteristics are part of their identity. A strong association exists between nursing socialisation and the individual's preconceived views around nursing (Johnson et al, 2007; Price, 2008). Altruistic vocabularies are common in the caring professions Fisher and Byrne (2011). However not all participants used an altruistic discourse within this aspect of their narrative; for Jane her memories of working with a child with learning disabilities led her to question the characteristics she possessed and whether she could be a nurse:

*I did my Health and Social care course for two years at college and then whilst I was there I did a placement at what was called a special school and it was the first time I had come across children with learning disabilities and I was in a classroom with children of about seven or eight years of age and there was a lovely little girl there who I saw have the most horrendous seizures and I actually fainted, and I couldn't believe when I came round I'd fainted because I was so upset about this child I couldn't believe what had happened to her. So I thought oh God I don't know if I can, can, look after these children if they're going to be doing these sorts of things as at the time I'd had very little to do with anybody with learning disabilities. (Jane)*

When describing sitting down with the careers officer to discuss what she would do after her Health and Social Care course, she remembers the little girl in the placement influencing her decision:

*Things that stuck in my mind were that little girl as it always has done, and I suppose he picked up the cues from that and he must have known, I don't know how, but he must have, I suppose because he's a careers officer, but at the time, you know, he said why don't you do this particular course. (Jane)*

Jane had other motivating factors to influence her decision to train as a learning disability nurse, as at the time nurse education had moved towards a centralised admissions service and the opportunities for applicants to apply for training across the country were more widely available, offering not only the opportunity to train as a nurse but also to have a significant change in lifestyle and move away from your home town. For Jane this was key in her decision making after speaking to her careers advisor:

*At that point in my life I was struggling with the fact that my grandmother was with us at home for so long, and really I wanted it as an opportunity to leave home. (Jane)*

Whilst struggling to accept her elderly relative living at home and not perceiving that she would 'cope' with caring for people with a learning disability, Jane's potential as a nurse was acknowledged by a careers advisor and the nature of nurse training at that time provided Jane with an opportunity to move away from home and her grandmother. Jane also reflects on this decision within her narrative and expresses this difficult situation:

*So it was just an awkward situation really. It was a situation that very selfishly when I look back at a 17, 18, 19-year-old teenager, I didn't want, so you know, and I just literally walked out and I got that opportunity to get that nurse*

*training and just left her to it which isn't what you'd expect now for me because I think oh God that's awful, but you know, you do what you do at the time don't you? (Jane)*

Jane's story highlights her personal identity development; a key motivation for Jane was to leave home, away from the 'caring' her mother had to undertake for her grandmother. This is an interesting aspect of the narrative, as Jane questions her ability to 'cope', not only with her grandmother but also with the girl she remembers at school. However, she describes seeing nurse training as an opportunity for this move, and also describes this as not being part of who she thought she was at the time:

*I didn't really know what I was going in to, you know, my plan had worked so far, I'd got away from home, I was going to be earning money, I had somewhere to live, that was... (long pause) yeah, the plan. (Jane)*

All of the participants' narratives had an element of describing challenges they faced on the journey to becoming a learning disability nurse, an uphill struggle to achieve the vocation they had chosen, in whatever form that choice had taken. In the study by Fisher & Byrne (2011), learning disability professional identity was bound with the emotional commitment to practice. The findings of my study suggest that the participants also used the narrative to articulate their 'emotional commitment' to learning disability nursing.

## **5.4 Conclusion**

The findings within the chapter suggest that the participants faced many challenges, but were still driven to complete their training. However, it is recognised that high levels of attrition exist in nursing nationally and studies suggest that there is a disconnect between expectations of nursing and the reality in practice settings. For learning disability nursing this disconnect is complex, as change in care practices in a macro and micro scale have impacted on the role of the learning disability nurse. A key theme for those interviewed in this study was around *becoming* a learning disability nurse, with all participants telling their story of how they came to choose learning disability nursing as a career and stories of their journeys through their nurse training to qualification.

Whilst existing studies have focused on nursing per se, and a minimal number of studies which asked specific questions of learning disability nursing students, there were no studies in the UK which sought the views of qualified learning disability nurses around their career choices using a narrative approach. Whilst for some participants they had experience of either working with people with learning disabilities or having friends or family who had a learning disability, some did not and chose learning disability nursing for a variety of reasons. All participants told of being drawn to staying within this field of work once they had some experience of working with people with learning disabilities. A number of the participants talked about the relationships that they developed with the people with a learning disability they worked with and how this had a positive impact on their choice of learning disability nursing. This suggests that for these participants their experience of working with people with learning disabilities reinforced their choice of learning disability nursing as a career option. The implications of this for the current recruitment issue for future learning disability nurses may include examining where 'experience' is now located following the closure of long-stay hospitals. Many HEIs have reported a decrease in the numbers of applicants to learning disability nursing, and this study offers a perspective on who chooses learning disability nursing and why. Data from the study with this focus has been shared through publication in the peer reviewed journal *Learning Disability Practice* (Genders & Brown, 2014), placing the findings into the wider learning disability community for scrutiny. A study by Price in 2009 had also focused on the recruitment of learning disability nurses and, whilst methodology differed, there are similar findings in relation to the reasons given for applying for learning disability nursing.

Literature also suggests that learning disability nursing as a specific field of nursing is not widely understood (Price, 2009), with the general public perception of nursing being around adult nurses in an acute setting (Price, 2009). The findings of my study suggest that learning disability nurses faced a number of questions about their choice of field of nursing and an acknowledgement that many family members, friends and other nurses were unaware of the existence of learning disability as a field of nursing.



## ***Chapter 6: On being a learning disability nurse***

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### **6.1 Introduction**

This chapter presents participants' discourses around 'being' a learning disability nurse, that period post-qualifying, and particularly describing their career pathways, rapid promotion for some, difficulties in finding the type of employment they hoped for, and their specific roles as learning disability nurses, highlighting connections to specific client groups. Participants also discussed their relationships with people with learning disabilities, a phenomenon that is discussed in detail within this chapter.

The concepts that underpin identity include perception of role, self-concept, and professional identity. For many participants their perception of their role focuses on role content, what it is the participants 'do', highlighting the specifics of the role and often using examples of individuals with a learning disability to illustrate their role. These aspects of the narrative describe the focus of all of the participants in the practicalities of the role, the 'doing' of nursing. Mitchell (1998; 2003) comments on the position of learning disability nurses in the 'family of nursing', suggesting that, since the inception of the NHS and nurses formally taking their place as an acknowledged discreet workforce, learning disability nurses have been on the margins as their role was challenged both within nursing itself and in the wider health policy arena. For learning disability nurses there have been many changes in service provision that has changed and shaped their role, but also role changes through promotion and career pathways have also shaped how participants in this study see themselves.

### **6.2 Carving a career**

Employment opportunities for nurses are explicitly linked to policy and practice within specific models of health care. Historically, large institutions provided nursing opportunities within a widely accepted medical model, which placed learning disability services within residential settings. However, the move towards community-based care post mid-1980s and the reduction in NHS beds following the 1991 Community Care Act initially reduced the numbers of learning disability nurses

required in these settings. The narratives of the participants around their experience post qualifying is a reflection of both policy change and of the subsequent changes in service provision for people with learning disabilities. In the narratives of all of the participants who qualified prior to 1995, rapid promotion was a key feature. In 1977, one participant, Robert, worked in a long-stay environment and described being promoted rapidly to charge nurse and then remaining in that position for some ten years:

*So I came and got a job here as a staff nurse, at (X), worked for a couple of years was promoted to be the charge nurse/ward manager, whatever it was called and ran and managed that as a place for, I've forgotten how many years (laughed) 10 maybe more (laughed) maybe less. (Robert)*

Employment within the large long-stay hospitals seemed to offer a career structure for learning disability nurses within the study, with many participants experiencing rapid promotion when the role of the nurse within NHS settings was clear. This was unusual within other areas of nursing, where promotion took longer and was often linked to additional training or development. For participants who were nursing at a particular time, the rapid promotion within learning disability nursing became part of the identity of the learning disability nurse. This was both an expectation and part of the individual's self-concept as someone who demonstrated the leadership skills required for promotion.

Another respondent, Matthew who qualified in 1981, acknowledged the move of many staff from the hospital environment to community during the implementation of the NHS and Community Care Act 1990), suggesting that this might have been key in rapid promotion:

*This was, you know, at the time the community care act just kicked in and the first phases of the closures and a lot of it was like firefighting because they were losing staff to go out to community settings. So I was there for about 18 months once I'd qualified and then a promotion came up and I became a charge nurse. (Matthew)*

Matthew comments here on feeling like he was 'firefighting', as the many staff moved from residential settings into community posts, however, the Community Care Act

was not implemented until 1990, and therefore what Matthew was possibly referring to Better Services (1971), which, according to Race (2007), took some time to implement due to its ambitious targets of a reduction in hospital beds by half from 60,000 to 30,000.

Ten of the participants in the study qualified between 1974 and 1990 and, of these, eight describe their career pathways and positive accounts of rapid promotion within learning disability services. For Paula, who also qualified in 1981, the rapid promotion to a charge nurse grade in the community from a deputy was seen as an achievement:

*In fact I'd just got a deputy for the post on (ward name) and I did about a month there when I was then successful in getting a community nursing post, and as I say I started that in the January 86. And community was somewhere where I'd got my aim, even through my training I'd loved the community both in general actually and in learning disability so that was where I'd had my eye and I could see that's the way it was going. So I was really pleased obviously to get that post, that was like a charge nurse post, so actually that was in 18 months. So you know I'd done very well really. (Paula)*

Similarly to Matthew, Paula achieved rapid promotion at a time when hospital beds were being reduced and many people with learning disabilities were living outside of the hospital provision. She acknowledged how community had been her chosen career pathway, and the timing suggests that Paula was in an ideal position when the community nursing service was expanding. Jane also noted fairly rapid promotion following qualifying:

*So I got my job as a... I was a D grade then, within about eight months I got an E grade. I was lucky to get a promotion staying on the same ward. Then two years later I applied for a Deputy's post which would have been an F grade. (Jane)*

Karen's narrative also had a focus on promotion and the perception that this was 'rapid' in this part of her story timeline:

*...qualified in 1982 and was rapidly promoted through the ranks I didn't just .. I was in that fortunate era where you automatically got a job in the hospital where you had trained but I did apply out of county to other hospitals and other services and was always offered the post but always was offered something extra back here 'oh don't go there H we will give you this...'. I*

*qualified in the October and I was in navy blue by February because there weren't many of us that qualified as staff nurses in that particular cohort so I would have been a fool to move. (Karen)*

The emphasis placed on these rapid promotions may be seen as part of the narrative of learning disability nursing around this time. As Paula stated, 'I'd done very well really'. The grading structure for nurses working in the NHS has been part of a framework known as the Whitley system since the inception of the NHS in 1948, giving a national structure to pay and conditions (Winchester & Bach 1995). However, leading up to the NHS and Community Care Act 1990 in 1983, a pay review body for NHS staff was set up to determine pay, whilst Whitley remained the framework for terms and conditions. The 1990 NHS and Community Care Act, however, gave some power to the newly-established NHS Trusts to create local terms and conditions (Corby et al, 2001). The participants within this study who had a focus in their narrative around rapid promotion and pay grade structures all describe this as a key aspect of their career between the early 1980s and mid to late 1990s, suggesting the importance of this aspect of their working life, not only in relation to hierarchy but also pay and conditions.

In addition to promotion within a traditional NHS hospital structure in the period after Better Services (1971) and prior to the Community Care Act (1990), the traditional roles of learning disability nurses within NHS hospital structures were changing. As more people with learning disabilities lived outside of institutional settings, fewer roles within the traditional structures in the institutions were available and many community posts had been filled by those staff wanting the leave the hospital environment. After the Community Care Act, the third sector had taken on a wider role of providing services for people with learning disabilities who had left the care of the NHS, creating an environment in which jobs for newly-qualified learning disability nurses became more difficult to find. Of the six participants who qualified post 2000, three participants described difficulties with initially finding employment in an area they desired. One participant, Debbie, who qualified in 2006, identified the difficulties of gaining employment after qualifying:

*It was another touch and go situation with the jobs I think there was, I can't remember numbers, but just say there was 12 of us and they were saying there was 10 jobs or something, so everyone was really worried and anxious*

*about the interviews but we all ended up getting one but it was just a fixed term for a year and they weren't fibbing when they said it was just fixed term, it was fixed term and it came to an end. (Debbie)*

It would appear from Debbie's account that there was some anxiety and worry around the employment situation. Although employment opportunities existed, these were of a fixed-term nature and not offering either a longer term commitment or a clear career pathway:

*It's uncertainty about what your role is going to be, in community jobs were like gold dust because people that had been in the Trust for ages, you know they were going to people who were at risk not people that were on temporary contracts. So that health home then closed and then I went to my other rotation and I left there just before it was due to come to an end and went back to the private care home that I came from, because I felt like it was a ticking time bomb just waiting till this contract came to an end and looking for qualified jobs was a struggle. (Debbie)*

Debbie's account, along with those of other participants, describe a period when the numbers of nurses working in hospital settings had dramatically reduced as NHS campus bed numbers fell. The changes in the employment patterns of learning disability nurses are reflected in the narratives across the 20 participants, highlighting a collective narrative of change in relation to the employment of learning disability nurses over three decades which has been described in the learning disability nursing literature (Gates, 2011; Jukes, 2002; Lowton, 2009; Mitchell, 2003). These findings suggest that the participants narrate a journey of change as services for people with learning disabilities change and offer learning disability nurses career opportunities outside of NHS provision. These changes to the underpinning philosophies of care have offered a range of roles to learning disability nurses, and this role diversity has been identified across the narratives of the participants. The following section focuses on aspects of the narratives that reflect this role diversity.

### **6.3 Role diversity**

Since the NHS and Community Care Act in (1990), services for people with learning disabilities have been delivered by a multiplicity of providers, some of whom have

traditionally employed nurses and many who have not. Inclusion as a policy and social movement has increased the likelihood of people with a learning disability accessing generic health and social care services, and the role profiles of the participants highlight the diverse roles that LD nurses now find themselves in in order to support and work with people with learning disabilities. The report Good Practice in Learning Disability Nursing (2007) suggested that the majority of learning disability nurses working in the NHS work in either health facilitation, inpatient services, or as specialist nurses - all areas which had reduced their capacity as more people with learning disabilities lived outside of NHS provision - and this is reflected in the narratives of participants who described diverse and changing roles. Additionally, studies by Brown (2012), Lowton (2009), Marsham (2012) and Mason (2010) highlight the role of the learning disability nurse in a range of diverse settings. Participants also described their feelings about their roles. Debbie, who is a health facilitator, describes both her positive and negative feelings about her role:

*This job has been really good and it's just been made permanent, which I'm really really pleased about. It's got its upsides and its downsides, I think downsides being that some days you don't feel like a nurse and you think you don't really have to be a nurse to do this job, so you feel a bit of a fraud, but then equally it's kind of celebrating the small successes I suppose of what you do because you do have a lot of them and until you talk about it and you see provision and it's kind of brought out of you then you do have to be specialised in learning disabilities. (Debbie)*

Debbie suggests that, although she enjoys her job, there are times when she does not feel like she is a nurse. This suggests Debbie has a specific view of nursing and her place within it, but also acknowledges the influence her specialist knowledge gives her in this role.

Narisa, who was an acute liaison nurse at the time of her interview, described with pride her role but also the potential for the future:

*Yes, and I'm proud of what I do, I love it and I've seen a difference what I've made, I've seen people have hospital treatment that they probably wouldn't have done if this role didn't exist and I'm not saying it's due to me, it's due to the process that I've put in...Well with this being a very new post, it's actually only temporary the contract for this runs out in May next year. it's 18 months and I'm trying to convince the trust that it's an ongoing requirement, so I'm doing lots of audits as well, but long term if this job's made permanent I've got a lot of plans to develop (XX) hospital to be sort of a service that certainly*

*supports the comprehensive needs of everybody not just a person with learning disabilities. (Narisa)*

Both Debbie and Narisa highlight 'uncertainty' about their role and jobs that they suggest are enjoyable. Narisa acknowledges the temporary nature of her current role and feels she is able to justify the continuation of the post should it be made permanent. She appears to suggest that the post has made a 'difference' to people with a learning disability accessing acute hospital services. Narisa and Debbie are both describing roles which are a direct result of policy changes, as health facilitation and acute liaison roles were advocated in Valuing People (DH 2001) as it became clear that the health care needs of people with learning disabilities were not being met within acute hospital settings. Lorna, her job at the time in health facilitation enabled her to envision a key role around public health:

*I had a health facilitation sort of role with looking at developing health action plans and personal health passports and things like that and then when I actually got my MSc came back to the public health department and put together a job description and a proposal and they accepted it. (Lorna)*

Lorna's position was similar to another participant, Julie, who describes identifying a 'gap' in communication services led to her employers creating a 'communication lead' role within her organization:

*I've added another string to my bow, I think it's almost ... Well it's an area that myself and my colleague we've seen a big gap in you know, in speech, not speech therapy as such but in communication support with people with challenging behaviour and autism. You know that as far as I'm aware, I've been told on a number of occasions by speech therapists, that there are no speech therapists in Leicester that specialise in challenging behaviour and every child, quite a lot of children that I work with the young people that I work with don't have any speech therapy input, although communication is quite clearly the significant factor in their behaviours. And yet I don't understand and I think that's where myself and my colleague, this is where our communication lead post comes from, it's that recognising, well actually, it's a massive area this is, and it's a big void that nobody seems to be filling and I think in my ultimate game, my ultimate goal should I say would be you know my dream job would be to work independently as a speech therapist, specialising in learning disabilities and autism and challenging behaviour, you know and marrying the two, you know. (Lorna)*

For both Lorna and Julie, a key aspect of their narrative was describing how they identified a gap in service, which they then created a proposal to fill that gap, and secured a niche post.

## 6.4 Creating a learning disability nursing identity

The creation of a nursing identity often draws on the speciality in which the nurse works. For example, a nurse working in an ITU setting may identify specifically with nurses working in this setting, joining associations and groups relating to the speciality of ITU nursing. The speciality carries with it its own identity; ITU nurses are seen to have many technical skills and are often high profile due to the level of need of the patients in that area. Conversely, nurses who work with the elderly are often less valued both by their nursing colleagues in other specialities, and by the media and general public as caring for the elderly is less attractive in our society. Literature suggests that a key aspect of nursing identity is linked to the speciality in which the nurse works. Historically, caring for people with learning disabilities has not been popular and, particularly, learning disability nursing has suffered difficulties in recruitment (Gates, 2011). Goffman's work in 1968 around stigma and courtesy stigma acknowledges the negative perceptions that can occur when working with a stigmatised group. Mitchell (2000), when examining the learning disability nurse in relation to marginalised groups in society, also picked this up.

Debbie uses the identifying acronym 'PMLD', which refers to people with Profound and Multiple Learning Disabilities, when describing how she felt when going to work in a hospice environment:

*I probably realised that I am actually more PMLD than I thought I was (laughing). I kind of always thought that I was mild moderate learning disabilities, a little bit of behaviour and a bit of banter (laughed) kind of thing but when you've got kind of the privilege I think to work with people that have got PMLD and high needs and particularly critical and end of life. (Debbie)*

Debbie attaches the descriptor of profound and multiple learning disability (PMLD) here to herself '*I kind of always thought I was...*' in attempting to describe the needs of people with learning disabilities and her identity as a nurse. She also suggests privilege here of working with people with complex needs. The role of the 'service



user' as a key to influencing identity is picked up by Hurley (2011) in his study of mental health nurses and their identity, suggesting that participants describe working with service users as a key area which shapes identity as a nurse.

David's narrative is based around the client group as he describes his role in relation to the people he has cared for:

*Then I went to the kind of semi-forensic area, the area that really interested me, because I've always been interested, the more challenging the client is is be... I mean I think you either get two sets of LD nurses, you get the ones who are really interested in physical healthcare and they will do... and that sort of stuff and you get the people who are really interested in challenging behaviour, I was the challenging behaviour, the more severe the better.*  
(David)

David appears to be identifying with specific client groups or types, but also suggests that learning disability nurses tend to fall into one of two types, based on the clients they are 'interested' in working with. Often people with learning disabilities have an identifier attached to them which links to the (dis) ability, highlighting deficits (Goodley, 2001), which allows a categorisation consistent with social constructs (Jenkins, 2007). A number of phrases are used throughout the narratives which categorise the people with a learning disability being described 'PMLD' (profound and multiple learning disability), 'babies' (profound and multiple disability), challenging behaviour, able, less able, mild, moderate. All of these phrases have meaning to learning disability nurses but mean little outside of the field. The relationships described by participants, both with people with learning disabilities and colleagues, formed a key theme within the narratives to be explored in the next section.

## **6.5 Relationships' as part of identity**

The narratives of 18 of the participants described relationships both with people with learning disabilities in their care and/or with co-workers in the 'community' of learning disability nursing. Discourse around their role as a nurse in relation to others may suggest that an important part of the identity of the learning disability nurse are the long-term relationships developed with service users.

Matthew described a long-term relationship with two people with learning disabilities who he initially started a piece of student work with. These two people have been used throughout Matthew's description of his career to illustrate care requirements. It would appear from Matthew's account that these two people are acknowledged as playing an important part in Matthews's career as he describes 'dedicating' work to them. Following their deaths, Matthew explained that he has continued to use the needs of these two people to highlight the work of the learning disability nurse:

*I met two people who went on to change my life dramatically who I've since dedicated a fair bit of work to... Obviously Lydia and David aren't their real names, I've mentioned them because there my key ones because if you know about me you'll know about Lydia and David because I used them in case studies... both of them sadly have since died, but during that period the staff group stayed with them and I think that was a tribute to the way in which I was able to get them (staff) to think about how people view their world, and finding that empathy and it was great to hear that right up until both of them died that the staff group remained with them. (Matthew)*

Matthew relates a substantial part of his identity as a nurse with these two people 'if you know me you'll know about Lydia and David'. Throughout his narrative, he describes the 'relationship' as one where David and Lydia received better care interventions, and he gained notoriety as the person who wrote about David and Lydia as case studies. The description of this type of relationship with people with learning disabilities could be interpreted in a number of ways. The suggestion by Matthew was there was equal benefit to the power balance, particularly when working with people with multiple disabilities is unlikely to be equal. When Debbie is describing a period in her training when she had changed to adult nursing she described the influence of one particular resident and how this brought her back to learning disability nurse training from adult:

*He has probably influenced me the absolute most, because when you do get really close to people and you're passionate about learning disabilities and their needs and stuff when he was in hospital and I was doing my adult nursing obviously it was his influence and the way that the staff were with him that made me change back. (Debbie)*

Robert also described a relationship with a service user who he worked with, presenting information about health nationally:

*We often did 13-hour days, and went all over the country and the message really was about, obviously taking forward the health messages, health issues from the team but also to demonstrate the ability of working in conjunction with somebody with a learning disability... we were very cohesive as joint presenters and the topic would slide between us effortlessly. (Robert)*

From his description, Robert appears to portray a level of relationship beyond what he would expect in his day-to-day role as a nurse.

Ryan, another participant, also described the changing nature of a relationship with a man with learning disabilities, as he became more of a 'co-worker' than client. Ryan describes his relationship as 'working together clinically'. Many nurses would recognise his description of this work as everyday interactions with their patients/clients, and not as a more equal relationship as suggested here. But like Ryan's relationship with M, these were not long-lasting and Robert acknowledged that the relationship changed when his job changed:

*It was because my job changed when I got back as well and so there wasn't that opportunity and I know that I felt really bad about the fact that I hadn't been able to maintain it, and whilst I would see him in various forums, and chatted out, he wasn't, he wasn't the same and yet, you know it, and yet I was very conscious of the fact that you know in one way I sort of felt I'd let him down on that but then I wasn't able to do anything about it. (Robert)*

Robert, Mathew and Ryan all describe relationships with people with learning disabilities that suggest empowerment and equality. It appears that the development of these types of relationships were encouraged at the time as the policy push and prevailing philosophies were more towards empowerment and normalisation. These relationships were able to demonstrate that service user involvement was possible. However, there are tensions around the balance between providing support which facilitates independence and friendship (Pollock, 2006; Fisher & Byrne, 2012). Stark (2010) suggests that 'emotional commitments could be construed as paternalistic whilst the study by Fisher and Byrne suggests that 'positive relationships were regarded as intrinsic to practice'. In addition to those relationships where a partnership approach developed, there were also a number of narratives around the influence that people with a learning disability have, including memories of training influenced by participant's relationships with the people with a learning disability in their care.

In Debbie's narrative, her focus is around the relationships she has with the people with learning disabilities she met when working part time before her nurse training. She has maintained contact with one particular woman and describes her as a 'friend'. Debbie said:

*I see her as a friend and an advocate when that's what I get put down as (laughed). Like, if she's ever having any difficulties with anything or there's some big meeting or I get asked to go because she can't she's more open when I'm around and I can understand her probably better than most people so I can translate for her. But yeah I've still been going on holiday with her every year... that's lovely like I love doing that, like last year we said when my job was coming to an end and I didn't know what I was going to be doing and I didn't have any holiday and stuff, I said to her you need to really start thinking about going on holiday with someone else now at (names residential home) – she said 'no no I don't want to', so it's difficult, it's a difficult thing because I can see it from both sides, it's her choice and she sees it then more as a girly holiday it's just normal, but if it's someone from work it's she's being taken (Debbie)*

Debbie's friendship described in her narrative is an example of the tension between what Pollock (2006) and Fisher & Byrne (2011) describe in their studies, the fine line between what is still a 'helping' relationship and true friendship. The discourse around the changing nature of relationships with people with learning disabilities can be seen as part of a historical timeline, where the possibilities for this kind of change in the nature of the relationship between the nurse and the person with a learning disability is time and culture specific, arising at a time when public perception of the rights of people with learning disabilities had undergone some change and the conditions in which people with learning disabilities and those who work with them find themselves.

In addition to the narratives around the relationships with people with learning disabilities, participants also discussed relationships with work colleagues and the wider nursing community. Lorna described the relationships within her work and used the analogy of a 'family', not only acknowledging the role of the staff, but also people with learning disabilities. Lorna describes the feeling of equality here, whilst acknowledging the power balance. For Lorna the long-stay hospital gave a sense of community:

*You know... you did meet... you lived and breathed... they were like your family really, I lived on site as well you know I used to go out In the hospital social club... I was very, I felt very much part of that community that...Nursing community, but also the wider community of people with learning difficulties who lived in that community, you know I was part of It, I wasn't any different from them. In a way, although I was a nurse so I recognise that I was more powerful but but there was something about being in that community that you go to the shops you'd see people from that community and you were, If you want, part of their community. (Lorna)*

Lorna's experience of working within a long-stay hospital and feeling a sense of community is one that is echoed in the literature focussng on life in institutional settings (Oswin 1973; Ryan & Thomas 1987; Gates & Moore 2002). Salmon et al (2013) also pick up this finding in their study of staff who moved from long-stay hospital-based care to community-based care. Relationships were a key theme within this study, with only one participant not shaping at least part of the narrative around this area. This participant became noticeable as an 'outlier' in this context, as the narrative had no focus on people with learning disabilities but rather on the specific career pathway this participant had taken. In the next section, the findings around change are explored as part of a major theme within the narratives in this study.

## **6.6 Challenge to change**

This section presents participant's discourses around change and challenge in their working lives. Participants discussed the ways in which they tried to bring about change to their practice and the practice of others. Some participants describe their involvement in large-scale change projects, while others describe how difficult it felt to influence change. Participants also comment on challenges they recalled in regards to their identity. Change is a key feature of all nursing and has been a key feature of the NHS since its inception. For learning disability nurses, the past 30 years has seen radical changes in the way in which society views those who learning disability nurses care for, the role of the NHS in that care, and therefore the role of the learning disabilities nurse commented on by a number of researchers over the past three decades whose main focus has been the impact of change upon services and the people who use them ( Emerson, 2005; Race, 1995; Ryan & Thomas, 1980; Owen, 2004; White et al, 2003). Change is a theme that is woven within the

narratives of all of the participants within this study. This key theme is represented through portrayals of the impact of change upon the way they work or have worked, the change they have attempted to initiate, or societal change more generally. Participants also describe their initiatives to drive change in the care of people with a learning disability, some of which had a local impact, whilst some had a more national impact. David describes his involvement in the closure of long- stay hospital beds:

*I came up here as a service team leader managing community homes, and part of that remit was to prepare the community homes, the NHS-run community homes for movement into community away from NHS and that's actually happening as we speak, and the last home should be moving in about a month and then all our campus beds should be gone in theory. It's been a long hard time, but in about a month's time we should have got them all. (David)*

David clearly sees his role as a key in the implementation of policies of community care and resettlement. His description highlights his role in preparing to move provision away from the NHS, which he does not see as a negative but as a positive move. He describes it as being a 'long hard time', acknowledging the difficulties associated with a major shift in care provision. Salmon et al (2013) suggest that participants in their study also identified 'hard times' and identify the 'challenge of change within others'.

Challenging outdated practices were a key feature of the narratives of nine participants who had spent part of their careers working in long-stay hospitals. These participants describe the long-stay hospitals and the staff who work within them in terms which suggest that influencing care was a challenge, with propositions of moving care practices forward often met with resistance, suggesting a contrast between 'old' and 'new' practices which is supported by studies by Jingeree & Finlay (2008) and Salmon et al (2013), whose studies both highlight this common theme of staff placing themselves as the 'new' in comparison to the 'old'. Robert recalls attempting to change practice at ward level when working in a long-stay hospital:

*I remember questioning why six blind chaps on a ward were paying for a television, that didn't go down well, because it was a big television that the charge nurse liked to watch. I remember moving the dining tables around because, and putting all the blind chaps together nearest the door so that they*

*had most easiest access, and at the next shift everything was back as it had to be and I thought, I'm not sure if you can beat them or join them on this one.*  
(Robert)

Robert's recollection portrays an attempt to challenge existing practice and to bring about change while recognising at times this could be difficult. As an early career learning disability nurse at this time, his lack of experience and status may have led him to question whether he could influence change in this situation.

In order for change to be initiated there often has to be a challenging of existing practice (Schein, 1999). This is not always easy, and Jane and Lorna acknowledged how difficult it could be to challenge practice at times, leading them to question whether learning disability nursing was for them. In particular, Jane had very clear memories about feeling she could not deliver care in the way she would like to:

*I was just really sad. I just thought, how can I keep going to work? I lived in the nurses' flat so I had to walk across the field to get to the ward that it was, and you know, it must have been the summer, coz I remember that the sun was always shining, and sort of, the sun would be shining when I go in and you'd walk in and you'd get that smell and you think, oh God, I've got all this to do and I can't do it the way... (Jane)*

Jane felt powerless to change things at this time, stating: 'But I suppose I felt a hypocrite because I was doing all these things that I knew weren't the right things to do, but I couldn't..., who was I?' Jane's feelings of disempowerment are clear and almost gave rise to her leaving nursing. However, as the following statement reflects, the resilience actually led Jane to continue in nursing:

*So I did find that very harrowing, but then, like I said before, if I just jacked it in then, they would still have been cared for like that and it wouldn't have got any better. (Jane)*

In a similar way to Jane, Lorna felt she could 'do more good' by not challenging but by 'working from within':

*And you learnt that sometimes you just could not challenge and If you did challenge you were out and you... would have been...you would have been you know sent out of the community really ostracised you know... actually I think you do think that you can probably do more good by staying in and*

*working from within than by challenging and being ostracised and thrown out and sometimes that does have costs. (Lorna)*

The participants who described these challenges fall into one of two categories; they recognised either that change needed to happen, but they did not feel empowered to do anything, or they actively fought for change and often perceived themselves as unpopular with colleagues. King (2006) identified that often these types of narratives contain an element of addressing social injustice. This is to be expected from learning disability nurses who have this as an acknowledged aspect of their education curricula (NMC, 2010) and an expectation of their role (DH, 2007; UK Chief Nursing Officers, 2012). However, as suggested in the study by Fisher & Byrne (2011), nurses who are engaged in changing practice and in practice transformation are not always in a comfortable position and the anxiety caused during the change process that Schein (1999) proposed can lead to defensiveness and resistance.

Mary, another participant in the study, also saw herself as a change agent from early in her career. She identifies within her narrative occasions when she had initiated change, but also acknowledging how personally difficult this was the time:

*And we again turned it around and made people key workers with groups, got rid of all the old clothes, got rid of the antiquated practices, but that was the most stressful time for me because the staff were absolutely against everything that I did. I was really a lone voice out there and that was the hardest fight of my career, and it was only because I had a supportive nursing officer that I think I almost survived it. (Mary)*

By using the phrase 'I almost survived it', Mary suggests that this was a particularly difficult time in her career but also suggests that that difficult time brought its rewards. She goes on to say 'so it turned around for me from the very worst place to the very best place that I worked'. David also describes challenging practices that were unpopular with his co-workers:

*Unfortunately I've had to go to court twice with work, both times when I worked in the hospital many years ago in (x county), I just happened to be in the wrong place at the wrong time saw stuff which really there's no place for any sort of care and I had to go to court twice with that, and I think both times the staff were struck off actually the Register as well as a result, but that was quite a hairy experience I have to say. (David)*



Participants not only described times when they had to challenge practice, but also when they felt their beliefs and values were challenged. Ten participants in the study highlighted this challenge to beliefs and values. Below are some of the phrases used to describe these feelings:

*I felt there was something very wrong about it. (Quinn)*

*I think from a professional point of view, my professional value base was being challenged on a daily basis, and it's not what, my philosophy of care... isn't how that is done. (Julie)*

*I could just remember thinking you should be out here you shouldn't be stuck in an institution, you know, so I suppose it was wanting to be a part of that and influence that you know. (Paula)*

*Although you knew it was not particularly right... well there was a choice you didn't need to do it but that's what the accepted behaviour. (Annette)*

Whichever approach is taken to initiating change, the narratives describe the process terms synonymous with difficulty or struggle. These narratives sometimes constitute internal emotional struggles with one's own values, and sometimes an external struggle leading to 'whistle-blowing' or reporting colleagues. David summed up his views on change in learning disability nursing in his narrative. Brackets and blue text (blue text) are used within the quotation to identify a change in tone to sarcasm, highlighting David's dissatisfaction with the attitudes of some of his colleagues:

*So I mean the one thing I believe that's been consistent in learning disability nursing is change, change has always been around, you think about when I first, my first career was working in large long-stay hospital with people with learning disabilities they were never going to close.....so, so we've gone from that to community homes run by the NHS (ooh so and so will die if he moves out the NHS. he needs nurse surveillance 24/7 and more if we can get it, well he doesn't actually does he just needs a nurse popping in every now and again to make sure he's taking his medicine, that his diabetes is alright really he doesn't ...doesn't actually need a nurse, yes he does, he'll die. I don't think he will,) so we've been through that to the NHS closing to you know I remember when we moved them into six bed units (deep breath)(ohhh revolutionary), and we even had some four bed units, even more... of what client care, of course now if you said you were opening up a four bed a four*

*bed house it would be, shouldn't they have flats or supported living or person centred planning or whatever you know. (David)*

Lorna also noted that change is often around the subtle things you do and part of who you are, your characteristic:

*I mean I think there are subtle ways that you make changes from within that are to do with you as a person and the way that you interact with other people and the way, you know, you're constantly.... you've always got students watching you and so things like the way you treat people, the way you might do a dressing; the way you respect and listen to people; the way that you engage with people on an equal footing rather from a, this is me that's you, you will do as I say, you know I think I would like to think that the differences that I made were to... and still make today... are from the way that I work as a human, you know that humanistic sort of quality. (Lorna)*

Personal approaches to changing and challenging practice is highlighted in different forms in all of narratives. Change appears through the narratives to be, as you may expect, in organisations and during a period of political, social and economic change. Discourses around change include those changes which are influenced by the individual but also change which is haphazard or unplanned (Lewin, 1958). The focus in the narrative is on the management of change, the active element rather than just the description of the impact. In keeping with the study by Fisher and Byrne (2011), it is also observed that participants reconfigure practice in accordance with official discourse, describing events and practices that were outdated at the time of interview but potentially not at the time of the actual events as requiring change. The next section explores some of the challenges to the identity of the participants in the study.

## **6.7 Challenged identities: 'Proper nurses'?**

In chapter 5 we see that, within the narratives of a number of participants, the routes into learning disability nursing are described as being a decision after initially considering other areas of nursing. For many participants their identity as a nurse was linked to the specific skills they felt they had or needed, so many undertook additional training to add to their skillset and perhaps 'legitimise' their role. Roberts's experience of attempting to bring about change led him to challenge his skills, and possibly his identity:

*I actually had very few role models as to and no understanding of the wider world of learning disability. Knew that things weren't as they should be but I didn't know what to do about it, to make it stand on its head and change. And so I decided that I would go off to the local general hospital and gain my RGN qualification, which I duly did. (Robert)*

After this training, Robert stayed within adult nursing for some time and only came back into learning disability after a move to another part of the country with his partner. This may suggest that, for Robert, his choice to retrain as an adult nurse was more linked to his beliefs and values than to the view that he might add some additional skills and knowledge to his profile as a learning disability nurse.

David suggests that the additional skills he could gain by training as a mental health nurse would afford him a skillset he could use within the forensic setting in which he worked as a learning disability nurse:

*Because I was in forensic and so many people with learning disability... you know between a third and one in three and half the people with LD have got mental health problems and I'd worked in forensics and loads of them had mental health problems, and I just really wanted to cement learning, and I learnt so much from it, but I also... I say learnt... they weren't... it was a different outlook. I've always been proud to be LD and I made it extremely clear that I would want to go, I wanted to stay in. (David)*

David, alongside others within this study, asserts that he undertook this additional training to improve his knowledge and skills as a learning disability nurse, rather than to change careers.

Lorna, whose father had initially persuaded her that her early career choice of aircrew was not suitable, had been unsure about her direction within nursing and had taken some years to decide where she wanted to be. After qualifying as a learning disability nurse and working with people with complex needs, Lorna felt she needed to undertake her adult training and suggested this was due to a perceived skills gap:

*As a staff nurse on a ward for men with complex needs and physical health problems, and thought well actually I don't really understand enough about the conditions that they had, they had leukaemia, renal failure things like that, so I went and did my general nursing. So I did 18-month general nurse training but went straight back into learning disabilities again. (Lorna)*

These narratives suggest a perceived skills gap related to the needs of the clients they were working with at the time. However, the desire to undertake adult nurse training may also relate to the social perception of nursing. Six participants describe not being a '*proper nurse*', or use similar phrases such as '*nursey nursey*' or '*real nurse*' to suggest they may not be perceived as a '*nurse*' and then go on to describe the ways in which they '*managed*' their career or continuing professional development in order to address this perception. Both Debbie and Narisa use the phrase '*proper nurse*', highlighting not only their own perception but also perhaps that of wider society:

*So I got a job at (name of hospice) children's hospice and so that would have been 2009 I think yeah last year and (name of hospice) really enjoyed feeling like a nurse, like a proper nurse (laughed). (Debbie)*

Debbie is not only describing what may be the perception of society around the work of a nurse, but also her own perception. Through using the phrase '*really enjoyed feeling*', she portrays an emotional response to performing a particular type of nursing role, suggesting in her previous role in learning disability she had not felt like a nurse. Debbie left this role after deciding that she preferred to work with adults, however, she has stayed on the 'bank' (casual staff database) for the hospice:

*Yes and I've stayed on the bank at (name of hospice ) so I've done a few shifts there and I think, I haven't done some for ages and I need to but if I keep, if I can keep the hands-on stuff. (Debbie)*

Here Debbie presents herself as a learning disability nurse who has a range of skills, reflecting that she can be 'hands on' and undertake 'proper nursing' if she chooses to. This is also a feature of five further participants who, within their narrative, described additional qualifications; Mary and Paula both describe undertaking a course that was available prior to 1983, which integrated two qualifications; learning disability and mental health:

*I started off doing just the learning disability registration and then swapped and did the integrated course, and whilst that was mental health and learning disability the one did help the other much later on. (Mary)*

Narisa, who started her training in adult nursing and swapped to learning disability, felt it was the right decision for her, however, her family were less sure about her identity as a nurse:

*So I have to admit it wasn't a popular decision with family, they well, I still joke now that I'm not a proper nurse. (Narisa)*

Soon after qualifying, Narisa worked within a social care model; however, she states that for 'her own peace of mind', she needed to extend her medical knowledge:

*Then I got a job away from learning disabilities and went to work in brain injury rehabilitation, again challenging behaviour, and it was quite intense but what that did serve to do was expand my medical knowledge because, although the training was brilliant and made you look at the social model of care, my medical knowledge was very limited as a result of following the social model quite strictly. so working with brain injuries was good for my medical experience, although it was very draining and you know you couldn't have done that for a long time for your own peace of mind really. (Narisa)*

At the time of the interview, Narisa was working as a liaison nurse in an acute hospital. This is perhaps an acknowledgement of her desire to maintain a focus within adult nursing and the medical model. For Narisa, her original desire to be an adult nurse may be influencing her choice of career pathway. Lorna also suggests that her choice to train as a 'general nurse' may have been based on an element of doubt over whether she was a real nurse:

*I think I really enjoyed my general nurse training, I think throughout my... before doing my general nurse training there was still this element of, you're not a real nurse, general nursing is the real nursing and I do wonder whether there was an element of me satisfying that about me thinking well I will go and do my general. (Lorna)*

*I think it probably comes from a little bit of everywhere I don't know that I could pinpoint one thing you know in those days if you said you were a nurse, and possible still so today although I don't know about so much now, they automatically think you're going to work in the general hospital. And I think that was probably... I mean referring back to this book that my dad had given me sort of when I was 10... well it must have been my mum and my dad but I remember discussing it with my dad. I think it was about a general nurse in a general uniform wearing you know in a ward where people were sick, physically sick and I think there was something about that that's about being a nurse that I probably did want to try and see whether it was my view of nursing or not, although I don't know that I consciously thought about it in that way. (Lorna)*

Lorna suggests within her narrative that she needed to 'try and see' whether adult nursing was for her, articulating the doubt she felt even after training as a learning disability nurse whether she felt like a 'real nurse'.

Historically, there has always been a challenge to place learning disability nursing within the broader field of nursing (GNC, 1926; Curtiss, 1959; CNO, 1985 cited by Mitchell, 2002). Mitchell went on to suggest that this opposition existed throughout the 20<sup>th</sup> century. The discourse around whether the participants felt they were proper nurses was a common theme within many of the participants' narratives and one that appears in much of the literature. The nurses in this study describe either building an additional skillset that they felt was missing as learning disability nurses, or by working in environments they felt represented 'proper nursing'. The next section focuses on elements of the narratives where the participants talked about their futures, both in relation to their personal journey but also more specifically learning disability nursing.

## **6.8 Challenged identities: vision of the future**

All participants in the study identified their current position as a learning disability nurse as a key part of their narrative even where they were not employed in a nursing role. While four respondents acknowledged that their time employed as a learning disability nurse was ending, a further 12 described the future either in terms specific to themselves or more generally about the future of learning disability nursing. In discussing her role as a health facilitator, Debbie recognised that there is less contact with clients directly, saying:

*Unfortunately that probably is the way it's going to be I think, unless you want to work in assessment and treatment. (Debbie)*

In this statement, Debbie states that is 'unfortunate' that she sees less of people with a learning disability, suggesting that this contact is something she values highly when working as a learning disability nurse. Paula also describes her current role as a nurse and the move towards managing systems and processes rather than working directly with people with learning disabilities:

*I am employed as a nurse so it is very much about the clinical role but it is increasingly over the years it is much more the management side of things and as I said before it's much more about the finances, things, again perhaps not so much in community. (Paula)*

*I feel now that we're sort of going down the same route as social services to a certain extent. We're definitely... obviously health care, we are in a business... but it feels more business-orientated now. (Paula)*

The changes to the NHS appears to have impacted on Paula's role, or at least her perception of it, as she sees the organisation as one which is more like a business and that this kind of work sits outside of the role of the nurse. Jane also comments on her current role and the perceived lack of balance with clinical work compared to managerial work:

*I've been a band 7 and a G grade for a long time and I accept that at my level I should have a good level of managerial skills, but I'm also at a level where I'm being paid to be a clinician and you know, the balance just doesn't seem to be... be right. (Jane)*

Both Paula and Jane acknowledge their continuing role as a clinician, but also voice some tensions around the 'managerial' aspects of the role. Maintaining systems and processes within an organisation like the NHS perpetuates the requirements of the people who use those services, in this case people with learning disabilities. Role tensions and role ambiguity around this discourse is picked up by researchers, including Majomi et al (2003).

Six participants in the study describe their views around the future of learning disability nursing. For Matthew, the role of the learning disability nurse, and therefore his identity, encompasses the ability to embrace change but also be prepared for the lack of nursing roles in the future:

*I mean, we're almost like the chameleon of the... You know... we just basically have to constantly adapt and evolve and change and I believe we'll still continue to because whatever societies legislates for people with a disability, people with learning disabilities will be affected by that, and we have to adapt to that that change of emphasis. (Matthew)*

Matthew's view about the future of learning disability is in keeping with the views held by many around the flexibility and adaptability of nurses, not just learning disability nurses (Chapman et al., (2008) Nunkoosing, 2000; Mitchell, 2002):

*I've always been about making myself redundant and I think the most important thing is, as long as you can be in the background supporting people and you enable people and empower people and you've shown them where, you know you take away the safety net you don't need to be there anymore. (Matthew)*

This point is a tension between empowering people with learning disabilities to live in a more inclusive society, and potentially removing the requirement for a specialist nurse. Another participant, Ryan, when describing his 'ethos', also noted this tension:

*I have an ethos that my job as a learning disability nurse is to 'do myself out of a job', that I should be working toward inclusion and as such there would not be a need for LDNs. (Ryan)*

Matthew and Ryan both acknowledge that changes in the construct of learning disability and subsequent shaping of service provision may lead to the demise of the learning disability nurse. However, other participants saw a clear role for learning disability nurses in the future, identifying the changes that were occurring within the NHS and services for people with learning disabilities:

*I always remember one of the first things we were told when we started training, dear old (nurse tutor name) said 'one of your main aims in life as a learning disabilities nurse is to make yourself redundant, you know because if you can solve all the problems you're not needed' sort of thing (laughing) and I think it's quite a good thing to remember, because you know, well I think people do panic sometimes, I think we do think that we could do ourselves out of a job, but that's just never going to happen. (Paula)*

Paula describes what she sees as the continuation of learning disability nursing as a career, stating that she thinks that there will always be 'jobs' for learning disability nurses. The role of the learning disability nurse within the changing nature of service provision is an ongoing debate, whilst the moves towards changing philosophies of care for people with a learning disability during the 1970s and 1980s shaped this debate as philosophies of normalisation and policies of community-based care took a hold. Today that debate continues as Government-commissioned reports like The Shape of Caring (Willis 2015) recommend the move towards a generic rather than specialist nurse.



However, the debate around the existence of specialist nurses also takes place in a broader philosophical context as the social construction of learning disability is influenced at macro and micro levels. In order for the role of the learning disability will need to be explored further to clarify how it is constructed in society which will in turn influence the debate about the future of the nurse. As Nunkoosing (2000, p55) states, 'our practices, place of work, authority and job title are all products of the knowledge we have constructed about learning disability'.

## **6.9 Conclusion**

This chapter focused on the aspects of the narrative that represent 'being' a learning disability nurse. The impact of uncertainty, role diversity, the importance placed on relationships within the narratives and change as a key theme. Discourses of change and challenge have been a key feature of the participants' narrativeS. This change is in the context of changing public attitudes towards people with learning disabilities, policy and service provision for people with learning disabilities accessing health care. The participants highlighted in this chapter describe change that they have tried to implement, their frustrations at times at not being able to implement change but also a recognition that change is inevitable.

The following chapter will draw together the discussion of the findings highlighted in chapters 5 and 6.

## ***Chapter 7 Discussion***

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### **7.1 Introduction**

This study has generated in-depth data about the working lives of the learning disability nurses who participated. Data within this study illustrates the journey into learning disability nursing and the experiences of learning disability nurses through their careers. This chapter will focus on and discuss the findings that represent a new contribution to learning disability nursing knowledge.

I have chosen to discuss 'becoming' and 'being' as key emergent themes within this study, and I will suggest the impact of experience identified in the narratives on the identity of the learning disability nurse, the shape, practice and influence on recruitment. In section 7.2, 'becoming' is discussed in the context of choosing learning disability nursing as a career, undertaking nurse training or education, and the impact of these experiences on a developing professional identity. In 7.3, the working lives of learning disability nurses are explored through the experiences of the participants in a changing service provision context.

The identity of the learning disability nurse is discussed in the final section of this chapter, exploring individual identity, collective identity, and the shaping of this through the experience of professional socialisation, public attitudes and the changing context of learning disability nursing. Initially all participants chose to narrate their story of choosing learning disability nursing, therefore this is a relevant place to start the discussion

## 7.2. Making career choices

Within this section, the concept of career choice and experiences as student nurses will be considered as represented within the study. A key theme for those interviewed in this study was around becoming a learning disability nurse, with all participants telling their story of how they came to choose learning disability nursing as a career. Whilst existing studies have focused on nursing per se, and a minimal number of studies that asked specific questions of learning disability nursing students (Owen & Standen, 2007), there were no studies in the UK that sought the views of qualified learning disability nurses around their career choices using a narrative approach. The biographical narrative framed interview, using a specific BNIM technique and utilising the Single Question aimed at Inducing Narrative (SQUIN) proposed by Wengraf (2001) as a basis for the interviews in this study, enabled the narrating of a story to encompass the thoughts around choosing learning disability nursing, but did not force this using specific questioning. All participants were asked to:

*Please tell me about **the story of your career**, starting from when you began to think about doing your nurse training **all the way up** to now.*

This 'prompt' led all participants to describe their journey into learning disability nursing, starting at varying points and emphasising (or not) the importance of this within the narrative as a whole.

All participants told of being drawn to staying within this field of work once they had some experience of working with people with learning disabilities. A number of the participants talked about the relationships that they developed with the people with learning disabilities they worked with, and how this had a positive impact on their choice of learning disability nursing as a career. This suggests that, for these participants, their experience of working with people with learning disabilities reinforced their choice of learning disability nursing as a career option.

This raises some questions about the impact of the changes in potential locations of work experience and may include examining where 'experience' is now located following the closure of long-stay hospitals. Many HEIs have reported a decrease in

the numbers of applicants to learning disability nursing, and this study offers a perspective on who chooses learning disability nursing and why. Data from the study with this focus has been shared through publication in the peer reviewed journal *Learning Disability Practice* (Genders & Brown 2014), see appendix 9, placing the findings into the wider learning disability community for scrutiny. A study by Price (2009) had also focused on the recruitment of learning disability nurses and, whilst methodology differed, there are similar findings in relation to the reasons given for applying for learning disability nursing.

Literature also suggests that learning disability nursing as a specific field of nursing is not widely understood, with the general public's perception of nursing being around adult nurses in an acute setting (Hallam, 2002; Owen & Standen, 2007), and McClimens & Burns (2016) suggest that the recent Willis report (2012) focused also on adult nursing in the acute sector. The findings of my study suggest that learning disability nurses faced a number of questions about their choice of field of nursing and an acknowledgement that they themselves, many family members, friends and other nurses were unaware of the existence of learning disability as a field of nursing. So why did these 20 participants choose learning disability nursing? The next section reports on the discourses around making that choice.

### **7.2.1 Choosing nursing: aspects of 'self'**

The nurses in my study, when narrating their career history, highlighted aspects of their identity that appeared to impact on their career choice. This was not only in descriptions of themselves, but also the descriptions of their journey to choosing nursing as a career and in their descriptions of the views of others. Early theorists, such as Mead (1934), suggested that this ability to see self in a particular way develops because of the way others speak about us. As such the language used in early socialisation is important, and being described as caring and helpful may be internalised and part of our self-representation and we may therefore act accordingly. The traits synonymous with nursing are often gender based, for example; female, caring and altruistic, the latter two generally being seen as positive traits, particularly in females. Parents who identify these traits in their (mainly) daughters at an early age may reinforce and encourage activities related to these, and may see a natural career progression as nursing based on the public perception

of nursing as a career. This reinforcement and encouragement to behave but also see the self in a particular way becomes internalised into a social reality (Berger & Luckman, 1966). The participants in this study who identify early childhood influences narrate stories of gender stereotypical discourses. They also use the same adjectives used by, particularly parents, when they were very young to describe themselves as adults, suggesting an internalisation of those elements of self-concept.

Identity is a fluid concept changing over time and many of the nurses in this study also identified influences in adulthood from significant others beyond immediate family. This included friends, other nurses, health and social care workers and partners. Identity in the narratives in my study is not only highlighted in the descriptions of self related to the perceived positive traits of nurses, but is in the more subtle descriptions of self which may allow people to make career choices at different points in life, for example being flexible or seeing self as a mature student, for example Narisa.

The discourse of 'self' within the narratives includes self-identification with nursing attributes aligned with traditional views of nursing, and this is particularly picked up when participants describe themselves prior to starting their nursing career but also how others had described them. Participants in describing aspects of their personality or identity as being congruent with their perception of nurses, with some identifying traits in themselves that they identify as being those of 'good' nurses. This may account for why a number of participants chose nursing more generally before finally undertaking learning disability nursing. General or adult nursing is the image of nursing held by the public, which has a place, usually the hospital, and a recognisable physical identity - female and in a nursing uniform. In imagining a career these recognisable aspects, coupled with the traits identified in nurses and admired by society; patience, altruism and caring, suggest a socially acceptable career pathway, particularly for young women. The participants within this study all articulated aspects of self that felt existed prior to commencing their nurse training, relating to values and beliefs widely accepted to be appropriate for nursing including, compassion, altruism and caring. This is in accordance with the findings of the broader study by Owen and Standen (2007) suggesting that, whilst the nurses in my

study felt these specific aspects were self-appropriate for learning disability nursing, they are articulated by many who would like to pursue a career in nursing.

### **7.2.2 Choosing nursing: educational attainment**

Since the development of new standards for nurse education by the governing body the NMC in 2010, all nurses now exit with degree-level qualifications with related changes in entry criteria (NMC, 2010). Prior to these changes, there were opportunities for nursing to be studied at diploma level, allowing those who had not achieved the appropriate educational qualifications to study at degree level to study for a career. Participants in this study identified nursing as a second option for career when they did not, or assumed they would not, achieve the grades required for their first choices. The implications of this have been seen within nursing, where it has often been seen as a vocational area of study choice, rather than academic. The history and place of nurse education has also played a part in creating this view, as the participants in this study who started their nurse training in the 1960s and 70s identify. Training was based within hospitals and students held employed status rather than student status, acknowledging its then vocational positioning. During this time, large long-stay hospitals for people with learning disabilities were major employers, drawing in those who wanted employment rather than a course of study. This history has left a legacy in that the educational qualifications required to study nursing have been changing consistently throughout the past 30 years, and more rapidly since the movement of all nursing & midwifery education programmes into Higher Education Institutions. This change, however, does not appear to be reflected in the public perception of nursing as a role that does not require a high level of educational attainment, reflected in the narratives of some participants who were encouraged to study nursing once other options became closed to them. Since the move towards an all-degree profession, this has changed. This change in the positioning of nurse education alongside other degree-level careers will have an impact on the choices people make, potentially mitigating against nursing being a second choice option based on educational achievement.

### **7.2.3 Choosing learning disability nursing in the context of changing service provision**

The narratives of the nurses in this study represent a period more than 30 years that has seen rapid change in health and social care policy, influencing the places in which learning disability nurses practice. The narratives of nurses in my study reflect this changing service provision, suggesting recruitment into this field of nursing has changed its emphasis as we have moved away from large long-stay hospitals as employers and a defined career structure within the NHS to a more diverse menu of career opportunities.

For the majority of participants in my study, learning disability nursing was not their first choice of career and this concurs with a number of studies (Beck 2000; Mooney, 2008; Rongstadt, 2002; Neilson and Jones, 2012). This is an important aspect as it may link with changing service provision and our current methods of recruitment to this field of nursing. Learning disability nursing today takes place in a wide range of settings, with fewer NHS campus beds and a smaller number of specialist services, often in treatment and assessment, and challenging behaviour or multiple and profound learning disability (DH, 2007; Gates et al, 2015). Understanding the motivations of students of learning disability nursing could potentially support appropriate recruitment strategies to this field of nursing at a time when HEIs are seeing a reduction in applications to this field.

Of further note is that the narratives in my study suggest that a previous experience of working with or having a friendship/family connection with people with learning disabilities influenced the choice of learning disability nursing. In the current context of people with learning disabilities accessing generic mainstream schools, health and social care services, and often living as part of our communities, the opportunities to connect with people with learning disabilities could be greatly increased.

### **7.2.4 Becoming a learning disability nurse: Aspects of resilience**

The narratives of the participants contain testimonies of resistance and resilience around not only their choice of learning disability nursing as a career but also, at times, the challenging of values in practice settings whilst they undertook their nurse training. Jukes (2013) also noted this within learning disability nursing, however, his

study was focused on a personal experience and observation. Therefore, I suggest, that my study builds and expands on his observations. The challenging of core values has been noted in studies of nursing more generally (Francis, 2013; DH, 2012), at a time when the recruitment of nurses with the appropriate core values is being questioned, (Ellis et al., 2015; Miller, 2015) and the recruitment processes in universities scrutinised. My study suggests that the nurses who participated articulated appropriate core values for nursing around caring and compassion, but they also highlighted many of the challenges of maintaining these values in the face of difficult and challenging situations in practice settings. Narratives included stories of students being challenged around their choice of learning disability nursing as a career, with the phrase ‘there’s no future in it’ appearing frequently. The nurses who faced this challenge discuss questioning their decision to train as a learning disability nurse, particularly where this challenge came from learning disability nurses themselves. This appeared in the narratives of nurses who trained particularly from the mid-1980s onwards, suggesting a view that the closure of NHS facilities and the policies of care based in the community and mainstream services would remove the requirement for learning disability nurses. At this time this was also being perpetuated by discussion and debate around the continuation of the field of nursing and a reduction of the numbers of learning disability nursing students commissioned (Gates, 2011).

Responses within the narratives suggest a sense of pride in continuing with their chosen career, in spite of negative views from others. There are clearly articulated discourses of resilience within the narratives around the experiences of being a learning disability student nurse, not only in challenges to identity but also in challenges around poor practice and the challenging of institutionalised rituals.

### **7.2.5 An evolving nursing identity**

This study suggests that the participants clearly remember their training as a learning disability nurse, even where that training was 40 years previously and describe many of the challenges around their identity. The nurses who trained the most recently described a clear student identity, one in which they were not employees of the NHS. However, those participants who undertook their training in the 1970s or early 1980s describe their ‘employment’ by the local health authority as



a key aspect of their training, they applied to hospitals and were often then recruited once they qualified into posts in those hospitals. Historically, this hospital-based education 'fixed' the student as an employee, and also part of a specific workforce and community. Descriptions of the relationships with other nurses and the fear of 'getting things wrong' suggest this close connection provided both a positive and negative experience. Studies which also focus on these aspects of nursing in long-stay hospitals include a focus on the positive and negative aspects of working relationships in these environments. Nurse education in the UK is now rooted in Higher Education, with all courses at degree level. Students studying nursing have full student status and, following the closure of long-stay hospitals, undertake little of their practice experience in institutional environments.

The changing nursing student identity is a key aspect of professional socialisation, as many studies acknowledge (Pask, 2003; Nelson & Gordon, 2004; Maben & Griffiths, 2008; Johnson et al, 2012), and for learning disability nurses particularly this has meant dramatic changes in the environments in which they practice their skills. For the nurses in my study who described practice learning environments outside of long-stay hospitals, they identified as learning many skills in a range of settings, often outside of learning disability nursing, as they experience other fields of practice but also a broader range of practice placements in non-health environments. As suggested (Johnson et al, 2012), these practice learning environments shape professional identity and, whilst my study did not specifically contrast those nurses who had a particular type of practice learning experience in long-stay hospitals against those who did not, this could be an area for future research. The fact that a number of studies have reported the importance of nurse education in influencing the development of professional identity and contemporary debate highlights the role of nurse education in maintaining and developing appropriate values and beliefs to ensure compassionate care in the future, a debate worthy of further exploration but beyond the remit of this particular study. This study has highlighted that all the participants had a 'story to tell' about their nurse training, which I suggest has shaped their identity as a learning disability nurse.

The narratives around 'becoming a learning disability nurse' focused on the decisions to train as a learning disability nurse, how the participants saw themselves

in relation to this decision, and the practicalities of 'doing' nurse training. Learning disability nursing has changed dramatically in the past 30 years and the impact of this has been seen in the recruitment of learning disability student nurses, the places in which nurses learning their skills and knowledge for the role, and in the attitudes towards people with learning disabilities in society.

### **7.3 The working lives of learning disability nurses**

This section considers change and its representation within the narratives of the participants. The working lives as described within the study have a key focus around change and therefore this will be explored as a prominent theme within the study with sub themes identified for the discussion as changing service provision, changing roles, and changing relationships. This aspect of the study focused around the discourses within the narratives post qualification, and of 'doing' learning disability nursing; the types of employment and career progression, diversity of roles, and the relationships within learning disabilities nursing. The collective narrative within this study suggests fundamental change in the settings in which learning disability nursing takes place, the practices learning disability nurses are engaged in, and their relationships with people with a learning disability. The impact of this upon how learning disability nurses see themselves, and how others see them, I argue has changed their nursing identity.

#### **7.3.1 Changing service provision**

The participants in the study reflect careers in learning disability nursing from the late 1960s through to 2002, narrating stories across a time span that has included major policy change. A key aspect of this has been the change in the balance of care provision for people with learning disabilities, with a move away from large long-stay hospitals towards a mixed economy of provision the within local authority, private, voluntary and independent sector. This study has viewed this from the perspective of 20 learning disability nurses narrating their journey through their specific period. This study uniquely highlighted the lived experience of 20 learning disability nurses in England as they work within a changing landscape of service provision.

The narratives of the participants reflect the historical changes in the care of people with learning disabilities, from hospital-based care, with its institutionalised routines providing boundaries for the nurses as well as the people with learning disabilities who lived in those environments. Participants, Annette, Jane, Paula, Matthew, Karen, Robert, Lorna, David, Tina and Mary, all began their nursing prior to the large-scale closure of long-stay hospital beds and policies of community care took hold. They narrate a story of harsh conditions, of difficult challenges to work within a system that often challenged their values and beliefs. For those participants who qualified in the early 1990s, and throughout that decade, they identify being part of a move towards community care for people with learning disabilities, with some identifying their career pathway matching policy change - as people with learning disabilities moved out of hospital provision, so too did some of these nurses.

The participants who qualified from the late 1990s onwards reflect the change in the shape of services for people with learning disabilities in their career choices post qualifying. Annette, Matthew, Karen, Angela, Jenny and Mary all work outside of NHS learning disability services in non-nursing roles, but continue to identify as learning disability nurses.

The narratives within this study when taken together reflect the position of learning disability across a historical timeline from the Jay report recommendations in 1979 through to Valuing People in 2001. Gates (2011), in his remit to report to the Nursing & Midwifery advisory committee at the Department of Health, suggests 'a revolution' in care provision for people with learning disabilities in the UK, and the narratives of the participants of my study illustrate some of that revolution with first-hand accounts of working lives of learning disability nurses. The development of nursing identity has a socio-historical context and, just as stories of Florence Nightingale shape the identity of adult nurses, the history of the Poor Law, workhouses, institutions and community care, shape the identity of learning disability nursing.

The stories of those working in the large long-stay institutions throughout the 1970s and 1980s mirror those experiences described by the published literature (Ryan & Thomas, 1980; Oswin, 1971; Potts & Fido, 1991). This serves to validate those

experiences and to suggest that the conditions in these environments were similar across the country and beyond.

### **7.3.2 Changing roles**

The role of the learning disability nurses over the past 30 years has changed dramatically in the context of the setting in which nurses work but also in the nature of the role. The collective narrative of the nurses in this study highlights these changes over a period of more than 40 years, and this section will explore change as a key theme within that narrative.

My study suggests that, for those who worked in the large long-stay learning disability hospitals prior to the 1990s, there were clear career pathways prior to the recommendations of the NHS and Community Care Act (DH, 1990) shaping service provision. These career pathways followed a trajectory of junior through to senior grades within nursing, either largely based in hospital wards or units, or, as the narratives moved towards the 1990s, a growing trend for nurses to be working outside of the hospital in community-based units. Studies documenting these changes to the role of the learning disability nurse have been set in a context of how service provision was, and this has continued through to today. The growth in the development of community learning disability nursing teams, the role of the health care facilitator, and other specialist roles undertaken in contemporary learning disability nursing practice, have provided a historical timeline for changes in role observed within this study as participants narrate their stories of working within a range of roles over a collective 30-year period.

For those working within many of the hospital settings, the narratives include accounts of rapid promotion within a nursing career framework, with many focused on role grades and the status, or suggestion of status, this brought. This focus on achievement and reward suggests clarity around role and role requirements to achieve additional status or reward. This focus also provides an opportunity to measure one nurse against another or self against others, shaping the identity of the individual nurse. In contrast, those participants whose career pathways didn't include long-stay hospital provision had little focus on a grading structure which related to pay bandings, but focused more on their job or role titles; health liaison nurse, public

health facilitator, or practice development nurse. These roles are often a direct result of the implementation of health policy, not specifically around learning disability nursing but more broadly, a key example being the Modern Matron role which was recommended following the introduction of The NHS Plan (DH, 2000) to give specific nursing roles a focus on the management of care. These titles, when used within the narratives, had an element of pride attached - particularly where these roles exist outside learning disability nursing. For example, the position Modern Matron is a nationally-recognised role within the health care sector and nursing and the connections with others who hold this title across the country were described as suggesting a professional identity beyond learning disability nursing.

Theorists like Jenkins (2001; 2008) suggest this aspect of identity that involves the measurement of self against others is crucial in understanding who we are (and who we are not). The changing nature of how we see ourselves as learning disability nurses and how others see us is intrinsically linked to these theories of social identity.

### **7.3.3 The challenge to change practice**

The changes in service provision for people with learning disabilities over the past three decades has led to a change in not only the places in which learning disability nurses work but also a huge philosophical shift in the approach to people with learning disabilities in society and in learning disability services. These changes to the way in which learning disability nurses 'do' nursing are documented in the literature in descriptions of roles and philosophical understandings outlined in chapter two, however, fewer studies document this change in practice from a historical perspective in a narrative form. Ryan & Thomas (1980), in their book based on a longitudinal study in long-stay hospitals, highlight some of the nurses' views around changing practice, while Oswin (1971) also focuses on long-stay hospitals and nurses' views around nursing practice. Gates and Moore (2002) present Annie's story, focusing on the narrative of a particular nurse whose career history spanned many years of nursing within an institutional setting. However, none of the studies mentioned focused on a larger number of specific learning disability nurses and their narratives of change as mine does. The narrative approach taken in this study, of non-directed storytelling, is also a unique feature of these stories of change, as the

participants choose to share those aspects of the story specific to change without suggestion or guiding to this area. This suggests that those stories of change are of key importance in the telling of their career history.

All 20 of the participants in this study describe aspects of change in practice, largely focusing on their role in attempting to change what they saw as unacceptable practice, reporting varying degrees of success. The narratives around changing practice have a 'up the mountain approach' to them, with reported personal efforts of moving practice forward, often in the face of resistance. This narrative is not only an individual story but also a collective narrative around the changes in learning disability nursing. For those nurses who had worked in long-stay hospitals this included moves towards greater empowerment for people with learning disabilities, better living conditions in long-stay hospitals, changes in institutionalised routines, and challenging of abusive practice. There is a shared understanding assumed in the language used about these hospitals and their practices, but also a clear view around the past and the present, an acknowledgement that they were part of the movement forwards in care practice.

Narratives in this study included clear examples of where the individual nurse acted as a change agent, moving change forwards, but also for those who had been nurses in the long-stay hospitals, a challenging of their beliefs and values. Whilst the stories highlight resilience, management of change, and elements of leadership, the narratives report a process synonymous with a struggle or difficulty. The impact of this upon the identity of the learning disability nurse and learning disability nursing is embedded in resilience and leadership. The literature around change and change management in nursing is vast, it is, however, limited within the learning disability nursing literature. The findings of my study suggest that experiences of change in learning disability nursing can be linked to leadership qualities as part of an evolving theory of identity in learning disability nursing. Whilst Jukes (2013) suggests that the publication of new standards for nurse education by the NMC in 2010 has 'strengthened the position of learning disability nursing', he suggests that 'in the context of complex care needs leadership is fundamentally important'. The move from institutional-based care, with its lack of focus around the rights of both those who lived and worked in those environments (Goffman, 1968), brought with it a

change in leadership style from what was often coercive and authoritarian to transformational and beyond. The narratives of participants in my study identify differences in leadership styles in both themselves and others, highlighting aspects of leadership such as resilience and self-awareness. These are identified as key components of managing change within the diverse environments in which learning disability nurses now work (Jukes, 2013). Leadership in learning disability nursing was part of a focus for the UK-wide learning disability consultant nurse network vision in 2006 (Northway et al, 2006), and the Strengthening the Commitment Report has identified a key area of leadership growth and sustaining of leadership capacity and capability (UK Chief Nursing Officers, 2012).

#### **7.3.4 Changing relationships**

Nineteen of the 20 participants had a clear focus in their narratives around relationships, suggesting emphasis for this to be a key part of their told story. These relationship discourses were focused either on people with learning disabilities themselves or on relationships with other nurses and co-workers. The emphasis placed on ensuring these relationships as a part of the narrative suggests that participants placed importance on bringing these elements of the narrative to the fore. This would be in contrast to areas of nursing where long-term relationships with patients/ clients were less common.

The findings from the narratives in this study suggest that the relationships the participants describe with people with learning disabilities had a key role to play in the participants describing who they were, their identity.

#### **7.4 Professional identity: Who are we?**

This final section considers the changing professional identity of learning disability nursing. The shaping of this identity and the articulation within the narratives of individual nurses forms a collective narrative identifying key elements of professional identity and the impact of policy change on roles, philosophical underpinnings of practice, and the way in which learning disability nurses see themselves and how others see them. Social identity theories provide a lens through which to view

nursing identity as a fluid concept, and where meaning is created through interaction and involvement with 'others' against which we measure ourselves. (Jenkins, 2008).

#### **7.4.1 The learning disability nurse as the 'Other'**

The learning disability nurses in this study not only described themselves in relation to other nurses but also narrated their perceptions of how other nurses saw them. The impact of this on the self-concept of learning disability nurses is noted through the discourse used during the interviews with these nurses. The phrase 'not a proper' nurse was common within the narratives, highlighting where this had been said to them but also where they perceived this to be true when measuring against 'other' nurses. A key to this, I propose, lies in the link between how society sees nursing, how nurses then see nursing, and then how nurses see themselves. The socially constructed nature of nursing in society also means that this identity is fluid, nursing as seen by society incorporates images of hospital-based care for ill people by nurses who are mainly female and wearing a uniform. This becomes part of the image of nursing and, potentially, who learning disability nurses measure themselves against when seeking validation of their identity.

#### **7.4.2 The self in learning disability nursing.**

The findings of this study in relation to self and the identity of the learning disability nurse suggest a number of aspects of self that I propose are both explicit and implicit within the narratives of the participants. These, I suggest, fall under headings of altruistic self; caring self; gendered self; compromised self; and powerful self.

A key feature of the altruistic repertoire in the narratives is around the phrase 'making a difference', which, whilst suggesting altruism, also suggests a focus on self. I identify aspects of the **altruistic self** in participants in the study who had a focus in their narrative on using phrases and elements of their story recognised as an altruistic discourse. Examples included phrases like 'making a difference' and '*making their lives better*' (Jenny). Chapter 5 highlighted many of the examples of this and it is important here to acknowledge that this is a socially accepted discourse around caring professions. Traditionally, nursing has been expressed as 'a calling (from God)' (Carter, 2014) and has continued beyond the religious aspect based on



more contemporary humanistic philosophies to embrace altruism as one of its underpinning principles. While psychoanalyst perspectives, such as those of Anna Freud, may focus on unresolved unconscious conflict driving altruistic behaviour (Freud, 1946), my study is concerned with the social aspects of learning disability nursing as a career and is not designed to attempt to measure the psychological motivations beyond what is reported within the narratives. The participants of my study who used an altruistic repertoire did so in a wider context of self, not claiming that this was the only motivation for choosing and staying in learning disability nursing but seeing it as a key part of who they were.

Altruism in the context of learning disability nursing creates tension, altruistic motives and the subjugation of one's interests to the needs of others may create disempowering actions, as altruistic motivations will often require reinforcement through the dependency of others. Whilst many of the participants within my study narrated a discourse around altruism, the history of learning disability nursing does not necessarily reflect behaviours from nurses which would suggest altruism. Chapter 2 has outlined the changing service provision for people with learning disabilities and the care within those environments that in many situations are not suggestive of philosophies based on altruism. It is suggested, therefore, that, whilst altruistic motives may form part of the reasons for wanting to become a learning disability nurse, these are motivations that are not necessarily translated into nursing practice when faced with the challenges of changing service provision.

Another aspect of self identification within the narrative is that of the **'caring self'**, with examples of how the participants saw themselves as caring throughout the narratives. These descriptions of caring varied from what might be perceived by some as stereotypical 'caring' roles - activities including washing someone, dressing them, or carrying out clinical procedures - whilst other roles may be less recognised within that stereotype. These included advocating and facilitating independence. In chapter 6, section 6.5, relationships with people with learning disabilities are described which have a range of functions for both the nurse and for the person with a learning disability.

These aspects may be defined as care within a nursing role but not necessarily understood as such by either the public or other nurses. This aspect of the role of the learning disability nurse is often part of the juxtaposition between perceptions of care and the reality of supporting people with a learning disability within a wide range of services. I suggest the literature base alluded to in this study, combined with the data from the narratives, supports the view that the debate around whether learning disability nursing should be part of the 'family' of nursing has stemmed from the stereotypical definitions of care and the caring role combined with perceptions of the nurse's role in relation to ill-health and wellbeing.

Caring as part of the nurse's role has also often been linked to gender, and the study has noted differences in the narrative of the men and the women within the study. This aspect of the narrative I am labelling the '**gendered self**'. For the males in this study there were fewer references in their stories to 'always wanting to be a nurse' or to 'caring' specifically. It appears from the narratives that there is greater emphasis on nursing as a career choice after other choices did not work out for them. There was also a greater focus for the men on 'networking', which they emphasised through the use of naming individuals well known within learning disability nursing nationally or those who it was assumed I would know. These 'connections' were described as influential in relation to career progression and development, with participants describing their networks using phrases such as 'the great and the good' (Matthew). A number of studies link networking with gender, highlighting the use of gender as an important strategy for the management of one's career (Forret and Dougherty, 2004; McGuire, 2002; Singh et al, 2006; Brink & Benschop 2013), and also suggesting ways in which networking may differ across genders.

For the women in the study their narratives are a closer fit to the stereotypes of nurse's roles, they describe themselves as caring, patient and supportive, but also highlighting their roles outside of nursing in relation to their family commitments. These links between the role as 'carer' or 'mother', it could be argued, become part of the identity of the 'woman as nurse'. Whilst the history of adult, or as it was known general, nursing was largely female, the history of learning disability nursing, going back to the days of custodial-style care and medical superintendents in large long-stay institutions, was dominated by male nurses (Mitchell, 1998; 2000; 2003). It is

suggested that the change in philosophies of care towards a more care-based model, rather than custodial, has shifted the balance towards a feminised model of care.

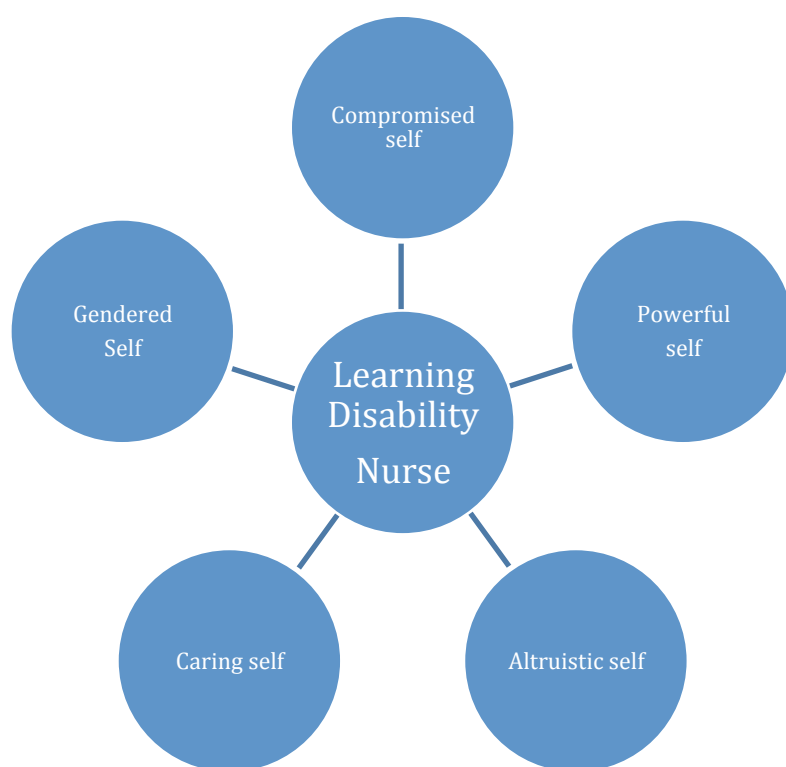
Within all the narratives there is an element of the story relating to conflict or compromise. This appears both when the participant is talking about their career choice prior to starting their training to be a learning disability nurse and once they begin their training. This, I propose is the '**compromised self**'. There are examples of compromise discourse in the stories of choosing nursing when another career could not be achieved. Participants described a range of 'first choices', with only three participants suggesting that learning disability nursing was their initial career choice. Section 5.3.2 in chapter 5 outlines the findings around 'testing times', when the participants describe some very difficult periods within their nurse training. Often this would challenge their values and beliefs, however, all of the nurses interviewed qualified as nurses, suggesting some level of compromise. This was suggested within their narratives told using phrases such as '*so I just got on with it then*' (Jane) and '*Although you knew it was not particularly right....*' (Annette). This element of the narrative suggests a feeling of powerlessness during this period as a student. These descriptions tend to change during the part of the narration when participants are describing their role post-qualifying, tending to demonstrate taking control and initiating and managing change. This is also evident in a number of elements of narrative where the participant is describing their life prior to choosing learning disability nursing as a career, but also taking control outside of their specific role as a learning disability nurse. These aspects of self I have labelled the '**powerful self**'. This aspect of self may relate to the power felt in making a career choice which was unpopular with family or significant others, for example Wendy, or when she was determined to complete her education even when ill:

*Because I was just so determined that nobody was going to stop me from being a qualified nurse. (Wendy)*

Across the narratives there are illustrations of the powerful self, also in the rich descriptions of challenging and changing care practices once qualified. Chapter 6 highlights these findings as the participants speak of rapid promotion and managing

change within organisations. These aspects of self are key to the individual identity of the participants and are multiplied. When examined across the 20 participants, we see common themes appear which may suggest elements of collective identity. Figure 4 illustrates these aspects of self.

Fig. 4 Aspects of self



Who the learning disability nurse sees themselves as is also influenced by external forces that could be seen to shape these elements of self. These include changes to the philosophies of care, service provision, education, public attitudes and policy change. The participants were able to recognise and acknowledge within their narratives this change, and the ways in which this might influence the future.

#### **7.4.3 Challenged identities**

Part of the narrative of all participants in this study was the focus on the future, either for themselves as learning disability nurses or for learning disability nursing more

generally. There is a tension between clinician or clinical aspects of the role and managerial aspects of role described by some and echoed in the literature in studies by (Brown et al, 2000; Crawford et al, 2008). There is a focus on 'doing nursing', with a value placed on the contact with people with learning disabilities described as 'hands-on' or 'with the clients'. Again, this focus portrays a specific view about nursing, that it is about the practical aspects of 'giving care' rather than shaping that care through policy change. A vision described by four of the participants and illustrated in chapter six suggested that the future might not include learning disability nurses at all, suggesting that the natural outcome of full inclusion would be that learning disability nurses would not need to exist. Again, this finding suggests a specific view of learning disability nursing and one in which the health care needs of people with learning disabilities can be met by nurses and other health care professionals who do not have specific learning disability expertise or training. Recent studies, however, suggest that with changes in the demographic of the population of people with learning disability and their health care needs that we need more, not fewer, learning disability nurses (Gates, 2011).

However, models outside the UK exist to demonstrate health and social care systems that do not include learning disability nurses, as the UK currently is the only country educating and employing this field of nursing practice as a specialism, and theorist Nunkoosing (2000) suggests that it is the social construction of learning disability, influenced at a macro and micro level, which maintains and creates health need and the requirement for a specialist practitioner. Since the interviews for this study, the increased levels of inclusion in mainstream health and social care provision have created risks for people with learning disabilities using generic services, as they often fail to meet health care needs. Reports, such as *Death by Indifference: 74 deaths and counting; A progress report 5 years on* (Mencap, 2012) and the Department of Health-funded *Confidential Inquiry into the premature deaths of people with learning disabilities* (Heslop et al, 2013) highlight unacceptable levels of avoidable deaths in the population of people with learning disabilities. In contrast, a number of high-profile investigations also highlight abuse of people with learning disabilities in residential services led by learning disability nurses, including the high-profile Winterbourne View (CQC, 2011). Whilst no participants in this study commented, views from learning disability nurses around the tension between

inclusion and mainstream versus specialist services could be an interesting area for future research.

#### **7.4.4 Collective identity and the learning disability nurse**

The creation of a collective narrative can occur when the construction of a group narrative with multiple narrators creates a story that, for this study, is the narrative of learning disability nursing over a 30-year period. Whilst the interviews in the study were individual, it would be remiss not to comment on the shared experiences of the participants and the creation of a collective narrative. Many approaches to narrative research (Atkinson, 1998; Clandinin and Connelly, 1994; Coles, 1989; Gergen and Gergen, 1986, 1988; Labov and Waletzky, 1967; Lieblich et al, 1998; Parry, 1991; Riessman, 1993; White and Epston, 1990) emphasise that individual narratives are connected to those of others. My research confirms the relational nature of narratives and reveals the social dynamic through which shared accounts are constructed. This, in turn, creates a collective narrative of learning disability nursing as aspects of being a learning disability nurse are combined with the history of learning disability nursing. In exploring the collective narrative of learning disability nurses I am reminded of the work of Jenkins (2008) in relation to social identity and its nominal and virtual elements:

Collective identification also has a nominal and virtual dimension. The nominal is how the group or category is defined in discourse, the virtual how its members behave or are treated. As with individual identification, these are conceptually distinct. In practice they are chronically implicated in each other, but there is no necessary agreement between them. (Jenkins, 2008 p.109)

The place of learning disability nursing in the collective of nursing has been questioned, as far back as the 1919 Nurses Registration Act (Mitchell, 2004) and, whilst nominal identity has been retained within the family of nursing, virtual identity has been affected. This is reflected in the narratives of individual nurses in this study when they describe their experiences of being 'put off' entering and continuing with their chosen career as a learning disability nurse. It also exists in their own questioning of whether they are a 'proper nurse'. The impact of this is that learning disability itself has, unlike any other field of nursing, questioned its own existence in the face of external scrutiny.

In contemporary learning disability nursing, whilst the nominal identity is stronger than it has been in the past, in that there is clear now support in relation to policy and the profession, the virtual dimension differs and the evidence in this study suggests that they perceive they are treated differently both by other nurses and by society. It is suggested that the diversity of roles of learning disability nurses is continuing to have an impact on identity, both for the learning disability nurse themselves and how they are perceived within the wider 'family' of nursing.

Understanding collective identity in nursing and in learning disability nursing is crucial to this study, as it locates the narratives within a particular perspective - how the learning disability nurse sees themselves in relation to others. In drawing on this emphasis, this study adds to the extant literature that has not previously explored this aspect of identity. The findings of my study suggest that learning disability nurses are aware of and acknowledge the differences between themselves and nurses from other fields of practice, and that this has often led to negative descriptions of their identity. This is reflected in a wide range of literature over the past decade highlighting the need for learning disability nursing to change. The language, including particular words or phrases used within the titles of this literature, raises questions over the 'future' and the profession. These include 'undervalued' (Hitchen, 2008), 'minority' (Karstadt, 2008), 'makeover promised' (Parish, 2011), 'envisioning' (Gates, 2011), 'time bomb' (Gillen, 2012), and 'fears for the future' (Sprinks, 2014). The authors of these articles are raising genuine concerns around learning disability nursing, but the negative language used within the titles of the pieces may lead a questioning of the role and function of the learning disability nurse. In addition, symbols are a crucial part of identity and belonging, as sociological theorists highlight the place of symbolised belonging in the context of collective identity, suggesting that symbolic boundaries are how we think and feel, rather than physicality.

Nursing has many shared symbols, however, the narratives in my study suggest symbolic boundaries between fields of practice have led to a separation within nursing which encourages nursing to use particular symbols of belonging to ensure collective identity. Theories of self-categorisation within social psychology, for example those espoused by Turner, suggest that when individuals feel threaten

externally they select, often unconsciously, collective identities with which to identify themselves and this in turn contributes to the construction of intra-group similarities and differences. The nurses within this study narrate their identity through their comparison with other nurses or other professionals, often being clearer about who they are not rather than who they are. This concern does not appear to be present for the dominant nursing field of adult nursing. The collective identity of adult nursing has been stable for some time, as the place in which nursing takes place and the symbols of adult nursing have been relatively static. However, the history of learning disability nursing appears to play a part in the collective identity of learning disability nursing, through the discourse of custodial-style care through to care underpinned by philosophies of normalisation that may have detracted from the nursing identity. It has been asked 'is there need for learning disability nurses if we propose in society that people live normalised lives?' Within this study both Ryan and David describe a future which involves 'making themselves redundant' in a society that has no requirement for learning disability nurses as it integrates those who have these additional needs into the mainstream of society. Whilst philosophically this has been an accepted view, in reality people with learning disabilities still utilise specialist services and the learning disability nurse has expanded their role to work in a wide range of settings.

The language of learning disability nursing allows others to participate in the collective. Unlike any other study, my findings suggest that the narrative used by learning disability nurses is not only an individual narrative but also a collective narrative, telling the story of learning disability nursing over a 30-year period, explicitly and implicitly identifying policy change that has shaped changes in the role and therefore the identity of the learning disability nurse. The narratives in my study highlighted shared rituals in institutional settings, but also the sharing of stories of relationships and struggle suggesting an assumption of the shared discourse of resistance and resilience told to one who had a shared understanding of the language of learning disability nursing. Over a period of 30 years changes in policy and in the roles of learning disability nurses has changed the make-up of learning disability nursing as a collective, highlighting differences in learning disability nurses has, in turn, highlighted the similarities of the group.



#### **7.4.5 Challenged identities: 'Not a proper nurse' revisited**

The challenge to the identity of learning disability nurses within the wider family of nursing is a product of a complex mix of historical challenge, uncertainty around role, lack of clarity around tasks nurses perform, and the constant change that learning disability nursing has been part of in the past half a century. Learning disability nursing in large long-stay hospitals where people with learning disabilities lived gave rise to challenges around whether this was truly nursing, and whilst Henderson's (1959) definition of nursing encompassed physical and psychological wellbeing, the historical impact of the workhouses and institutions becoming NHS hospitals following the inception of the NHS in 1948 left questions around whether this was nursing at all (Mitchell, 2001). The discourses within the narratives around which the participants are as nurses are a reflection of not only the history of learning disability nursing but also the perception of the identity of nursing per se. A key aspect of this for some of the participants was tied into the role or task they were involved in, and whether this was perceived to be 'nursing work'. A finding of this study suggests that, if learning disability nurses feel that they have a 'skills gap' or if the opportunities may be better in another field of nursing, they may undertake additional nursing qualifications, however, there are fewer opportunities currently for nurses to do this due to changes in the way nurse education is funded. Lorna, in particular though, reported using the opportunity to train as a 'general nurse' to test her career choice and perceptions about nursing. Crawford et al (2008) in their study of mental health nurses also found that nurses might use additional qualifications to leave nursing altogether. This was not echoed in my study but may have been a finding if I had interviewed nurses who had left learning disability nursing.

In focusing on the debate within learning disability nursing on the 'who we are not' rather than the 'who we are', we may have caused a collective crisis of identity. The uncertainty formed through a historical challenge to the place of learning disability nurses, coupled with an uncertainty from within the profession itself, has provided an opportunity to continue asking the question 'Is this nursing?' The Nursing and Midwifery Council in recent years has added to this uncertainty around the future as consultation documents ask 'do we still need a specialist field of practice for learning disability nursing?' (NMC, 2010) and, more recently, the recommendations of the Willis Commission suggesting the move towards a generalist nurse (Willis, 2015). As

the professional and regulatory body of nursing, the Nursing and Midwifery Council, consults again on a new set of educational standards for the education of nurses, it appears to some that the question of the existence of learning disability nursing is being raised again.

## **7.5 Concluding discussion: Towards a new model of learning disability nursing identity**

Whilst the study suggests a growing confidence in identity on an individual and collective basis, there is still a challenge around public identity as the image of nursing remains fixed on the 'traditional' notions of nursing, compounded by images of uniforms and hospitals. The media portrayal of nursing today includes social media, an area in which nurses have also been able to generate social capital through links with other nurses. Public perception, however, remains focused on nursing as a low paid, female-dominated profession, based in hospitals. This negative image is reflected in learning disability nurses' self-image that in turn is then reflected in the nurses' presentation of self-influencing public perception. While learning disability nurses describe themselves, as 'not proper nurses', society will assume the same. Many of the nurses in my study highlighted public perceptions in their narratives, their families, friends, other nurses, all represent the public view of learning disability nursing. In the early stages of choosing learning disability nursing many reported negative views

Understanding identity from both an individual and collective perspective allows for diversity, it is ok to be different within a collective, and therefore this is the case for learning disability nurses within learning disability nursing and for the collective of learning disability nursing within the wider family of nursing. The narratives within this study have offered individuals an opportunity to negotiate their identity, to present an image of themselves for acceptance by another. Identity as a learning disability nurse was clear in the narratives, but these were being listened to, read and interpreted by someone from within that collective with a shared understanding. Individual nurses know who they are and what they do, however, the public know

less and, as a profession, there have been difficulties articulating the learning disability nursing identity.

Social Identity Theory offers a framework on which to consider the professional identity of the learning disability nurse. The findings in this study suggest that the professional identity of learning disability nurses is shaped through the following:

- Individual identity
- Training and education
- Working lives
- Collective identity

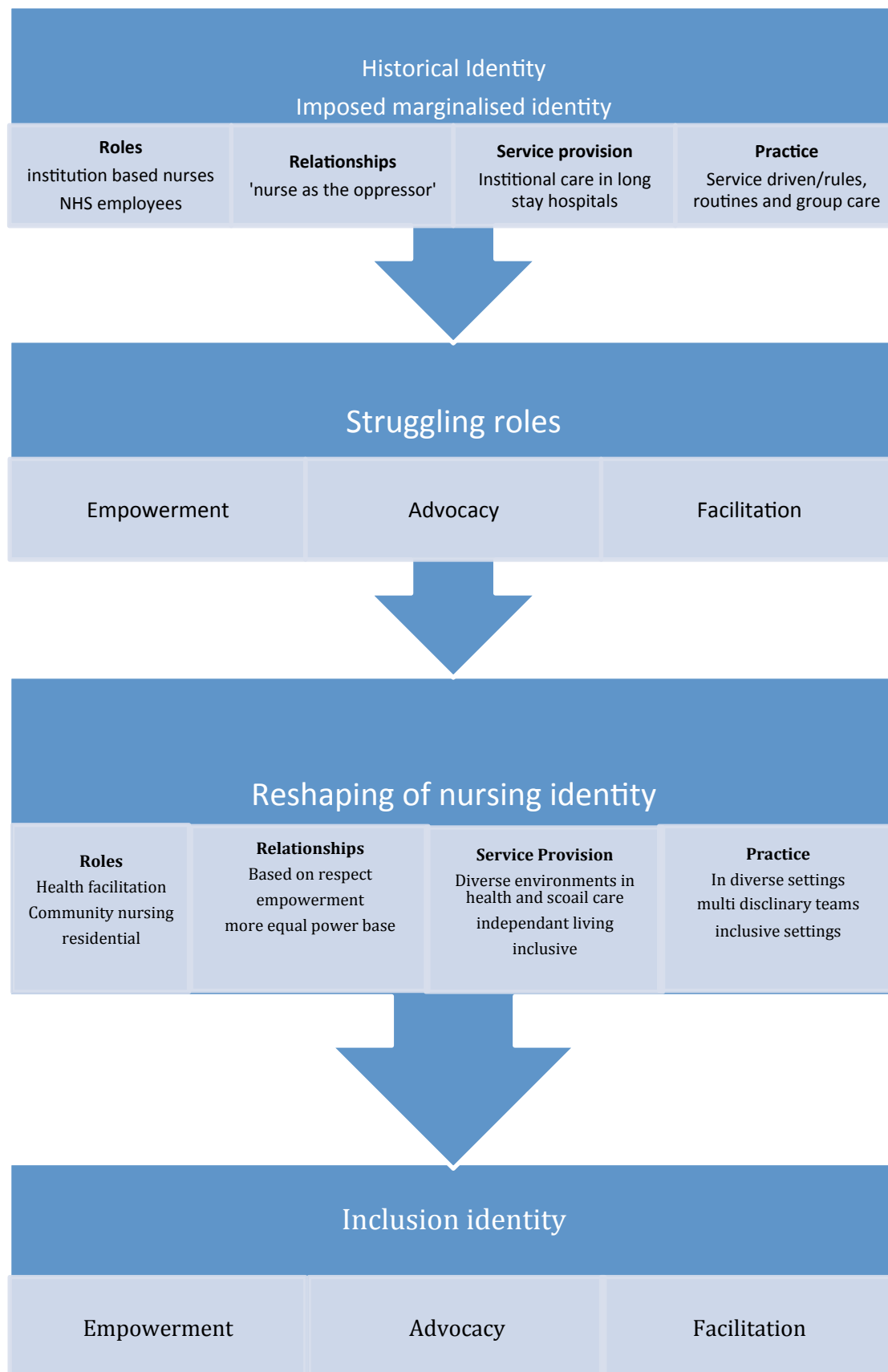
Individual identity was articulated through the values and beliefs suggested as held by participants but also the reasons and justifications suggested for choosing learning disability nursing as a career. Training and education is a key influence in the creation of professional identity, and narratives of the participants in this study describe challenges and reaffirmations of their choices of learning disability nursing as a career. The working lives of the participants when taken as a whole represent a diverse range of employment within and outside the NHS, and the suggestion of a tension within the perceived identity of a nurse and that, more specifically, of the learning disability nurse, which was highlighted in the numbers of participants who describe themselves as 'not a proper nurse'.

The participants also embed within their narrative notions of collective identity, identifying the key relationships with other learning disability nurses but also using a common language to describe themselves. The creation of this new learning disability nursing identity takes place in a historical context of change; changes in service provision, in employment opportunities, in education, and in the way in which society perceives people with a learning disability. The past 30 years have seen significant change in all of these areas, making it timely to reconsider the identity of the learning disability nurse. Recent report *Strengthening The Commitment* suggests the values of the learning disability nurse (UK Chief Nursing Officers, 2012) but does

not suggest an identity model which could provide a framework for recruitment, education and employment, of learning disability nurses across the UK.

Understanding the learning disability nurse through their narrative facilitates an understanding of components of identity and through this we are able to interpret the meaning of being for learning disability nurses. Previous identity models have focused on a 'hidden' profession and oppression and marginalisation, with some associated stigma (Goffman, 1968). It is suggested that the learning disability nurses participating in this study, whilst highlighting elements of marginalisation, narrate a strong identity around advocacy, empowerment and facilitation. Fig 5 represents this transition in identity over the past 30 years that is highlighted by my study.

Fig. 5 Identity transition



The benefit of articulating this model should be in the opportunity to use this to consider who the learning disability nurse of the future will be. This study is unique in its focus, specifically on using the narratives of learning disability nurses to create an identity model of this kind. This could have wider international benefit as many countries consider the place of nurses who care for people with learning disabilities within either a generic or specialist context.

The final chapter of this thesis, chapter 8, will focus on the implications of the findings of this research study for education, practice and further research, and acknowledge the limitations of the study.

## ***Chapter 8 The place of this study in learning disability nursing: reflections, limitations and moving forward***

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### **8.1 Study limitations**

This study utilised a qualitative approach using narratives and was based only in England. A small-scale study such as this will always have limitations based on size and scale, which are acknowledged fully by the researcher. There has also been rapid change in learning disability nursing in the past five years and, as a part-time PhD student, these changes are beyond the timeline of this study. The narratives provide a rich source of information and the telling of the story is as valuable as the story itself. Within the scope of this study, I have not been able to share more of the ways in which the story was told. Whilst the sample size was small, this is relative, and for the method of interviewing utilised here (BNIM) the sample size is larger than is common. While this enabled me to have some diversity within the nurses' roles inside and outside of the NHS, it provided challenges in ensuring the voices of all were heard.

### **8.2 Implications for education and practice and research**

The findings of this study have wide-ranging implications for education, practice and research. All courses based in HEIs, leading to registration as a nurse or midwife in England, at the time of the study are funded and commissioned by commissioning bodies negotiating with NHS Trusts based on workforce planning.

#### **8.2.1 Education: Commissioning**

This study has been located in England and, at the time of the study, both pre-registration nursing and elements of Continuing Professional Development (CPD) have been commissioned through a commissioning body. For pre-registration nursing, as previously noted, the commissioned numbers for learning disability nurses have fluctuated over a period of years and have, more recently, increased. However, the numbers of HEIs offering learning disability nursing as a field has decreased and therefore we are still seeing an overall reduction in numbers (Gates, 2011). Commissioning for pre-registration nurse education in England is currently connected to workforce planning models predicting the future workforce needs,

however, this is complicated in learning disability nursing by the increase in service provision outside of the NHS and a lack of data on how many LD nurses are employed as nurses but in non-NHS employment. This study has highlighted the variety of roles undertaken by learning disability nurses both inside and outside of the NHS, however, further research would be required to understand the connection between educational commissioning and the destination of learning disability nurses in non-NHS settings.

There have been changes to funding arrangements for CPD with devolution to local hospital trusts in many areas, however, a large proportion of learning disability nurses work either outside of the NHS or within the NHS in non-learning disability areas, for example the acute liaison nurse role. Whilst this study did not focus specially on CPD, the changing role of the learning disability nurse and the impact of this on CPD requirements cannot be ignored and could be an area for potential further study, questioning the role of commissioning for post-registration education in the wider context of service provision.

### **8.2.2 Education: recruitment**

The implications of the findings of this study for education underpin not only recruitment to pre-registration nurse education for learning disability nurses but also the curricula within Continuing Professional Development (CPD) and post-registration education provision. The finding of this study suggest that the perception of nursing broadly is still that which represents a specific field of nursing, and even further an acute focus on nursing with its symbolisation around the sick, nurses in uniform and hospital-based care. There is a broader implication for this perception as nursing has and is changing. The move towards care based in primary rather than secondary care settings is reframing the role of the nurse, and, whilst the media may still portray nursing to be acute accident and emergency focused, the public, who become our applicants, may see little else of nursing practice. This is further complicated within learning disability nursing where the opportunities for people to undertake work experience or work alongside people with learning disabilities in settings where they will meet learning disability nurses are becoming more limited. Whilst national campaigns to raise awareness of learning disability nursing have been discussed, the numbers of applications nationally has been decreasing and in



recent years, whilst the numbers of commissions for learning disability nursing students has been increasing. This study's findings suggest that experience of either knowing someone with a learning disability or working with someone who has a learning disability has been a key factor in participants seeing this as a career opportunity. The impact of this and other studies that ask why people enter learning disability nursing need to form part of the 'intelligence' to support marketing campaigns. Only around 40% of universities offering adult nursing have been commissioned to offer learning disability training. The decreasing number of universities offering learning disability field of practice may suggest a lower value placed on this field of nursing, both outside and within the profession.

In many HEIs, marketing for pre-registration nursing across four fields of nursing is managed as one brand and the distinction between the fields is not always taken into account. Educators in learning disability need to ensure their field is represented to the public, and therefore applicants, in a manner that represents the identity and contemporary practice of learning disability nurses.

### **8.2.3 Education: Curricula**

The findings of this study suggest that the education of the learning disability nurse is key in forming professional identity, and this is supported by a variety of studies from the broader body of nursing literature. Howskins and Ewens (1999) suggest that professional socialisation is much more than learning the skills and knowledge specific to a particular role, but is also about the values and norms associated with that profession. During nurse training, students may be challenged by environments and care practices that they think may not support the client. Practice learning experience has been the focus of the narratives within my study in the development of an identity as a nurse, but also in the complex development of skills around change management and leadership. Jukes suggests that preparing learning disability nurses 'psychologically' in self-awareness, conflict resolution, emotional intelligence and personality development enhances their leadership in challenging practice settings.

The curriculum at pre-registration level provides challenges around ensuring all nurses are able to respond to the 'health care needs of all people who come into

their care, including people with learning disabilities' (NMC, 2010 p.17). The changes to pre-registration curricula have created a framework to enable all nurses to understand the fields of nursing, however, it has been suggested that this could be a route to generic nursing rather than specialism. As the writing of this thesis comes to an end the Nursing and Midwifery Council are beginning the development of a new set of educational standards due out for consultation in spring 2017 with adoption by all higher education institutions by 2019 (NMC 2016). The NMC have been clear that: 'The new standards will apply across all current fields of practice and all healthcare settings, from acute to community. They will give all nurses, regardless of field, an understanding of mental health care and physical care. They will also reflect the growing focus on public health and health education' (NMC 2016). Whilst for some the interpretation of early messages might suggest a more generic rather than specialist focus in the new standards the consultation period will offer the opportunity to explore the identity of nurses from specific fields like learning disability and the impact of any change to education.

A number of reports have supported the place of education and training in preparing the workforce for the delivery of high standards of health care for people with learning disabilities, however, recent inquiries into standards of care, both in specialist learning disability services, for example as part of the Winterbourne enquiry (Flynn, 2012), and in mainstream hospitals (Ogden, 2016; Mencap, 2012), suggest abuse and neglect, and in our communities a growing concern around hate crime (McDonald, 2015; Richardson & Beadle-Brown, 2016) and 'mate crime' (Landman, 2014; Doherty, 2015; McDonald, 2015; Tyson & Hall, 2015). My study has identified a professional identity that has largely been based around feelings of marginalisation, disempowerment, and a lack of confidence in the place of learning disability nursing in the wider family of nursing.

Contemporary learning disability nurse education aims to ensure nurses are 'fit to practice' in a wide range of health care environments, underpinned by both health and social care models of disability. Philosophically too, the curriculum needs to support the developing identity of the learning disability nurse who may feel marginalised in programmes and courses where there is a focus on the more dominant (and larger) fields of nursing. Curriculum design needs to be cognisant with

contemporary nursing practice and also the future of nursing practice across all fields of nursing. In post-registration or CPD programmes, there is a challenge around providing appropriate courses and programmes at all academic levels that support the diversity of role in learning disability nursing practice. This CPD may also be outside of nursing programmes within the social or biological sciences.

#### **8.2.4 Implications: Practice**

In the context of this study I have considered 'practice' to be anywhere where the learning disability nurse is employed. Therefore, the implications of the findings of this study are wide ranging. In relation to identity, a key finding is that the participants identified as learning disability nurses even when working in non-nursing roles. In order for this to be useful, further research around what it means to be a learning disability nurse in a non-NHS or non-nursing organisation is required. Further, a key finding is that practice shapes identity and the challenges and opportunities within the practice setting can confirm the identity (or not) of the learning disability nurse. Learning disability nurses are working in a diverse range of settings, often alongside nurses and other health care professionals outside of their own field of practice, and Gates and Mafumba (2015) have suggested that learning disability nurses will need to have a strong and confident identity to work in these environments. Jukes adds to this, suggesting:

Given the political and social context above, and where intellectual disability nurses are located, there is no doubt that they have a clear impact, identity and influence as trailblazers and champions. This occurs particularly within the health care arena, where they promote and support health equality in access to generic mainstream services and acute liaison teams. It is at this interface of services where they are required to demonstrate their values, impacting on service users and services, and working towards a vision that empowers and motivates a workforce across sectors. (2014. p.8)

Jukes suggests that networks may be important for sharing good practice and supporting practice locally, but also suggests that evidence points to the fact that: 'Intellectual disability nurses are required to break out of their professional boundaries, be more transparent across other sectors and professions, extol their capability in collaborative working, and avoid becoming parochial' (2014. P.11).

### **8.2.5 Further research**

There are some gaps within data relating to learning disability nurses working outside of the NHS, and this causes difficulties in ensuring research about learning disability nurses has an inclusive approach. Research around the professional identity of the nurse is plentiful, however, research which focuses on the learning disability nurse and their identity is very limited and usually focuses on the role of the learning disability nurse or on our values, rather than a combination of these things. I find this interesting when we have been asking 'who are we?' for many years. Maybe the answer has been in waiting for others to tell us or waiting for policy to guide us. Recent health policy around learning disability nursing has been clear in its commitment to the requirement for learning disability nurses. Learning disability research that focuses on the nurse rather than the person with a learning disability or the interventions has been limited. As learning disability nursing faces continuing change and challenge, further research which helps to provide an evidence base for the development of a strong nursing identity would be beneficial to the profession.

### **8.3 To conclude...**

The services to support people with learning disabilities in society have changed shape and philosophy over the past three decades and with this learning disability nursing has changed. The NHS has been a provider of health services for people with learning disabilities since its inception, employing nurses to historically provide care in hospital settings through to a today's learning disability nurse working across a range of services with a diverse role. I began this study interested in how learning disability nurses saw their role, their identity and people with learning disabilities across a thirty-year history to try and capture some of these changes from their perspectives.

The findings of my study suggest the challenge to the identity as a nurse came not only from those outside of nursing, including family, friends and other nurses, but was also internalised into descriptions of self, 'not a proper nurse' was a phrase used specifically by those nurses who had trained post 1990, suggesting that as the nursing role became more diverse and the hospitals began to close, the

symbolisation of nursing changed, challenging, for some, the sense of belonging to nursing. This finding also links to many of the discussions and debates around the place of learning disability nursing in the wider profession which occurred following the NHS and Community Care Act 1990. This study is unique in exploring the narratives of a number of learning disability nurses in England, and for this to focus on their professional identity developing a body of evidence suggesting that learning disability nursing identity needs to be strengthened in relation to its position within the profession of nursing.

This study has captured the stories of learning disability nurses; their reasons for choosing this field of nursing as a career and their experiences in their roles. Identity became a key feature as their narratives explored who they were not only as a nurse but also as a person in the context of working with people with learning disabilities. Many of the narratives focused on challenge and change, an aspect of learning disability nursing history captured in the literature.

This is the only study of its kind in the UK which focusses on the narratives of a number of learning disability nurses in order to explore the identity of this professional group. The history of learning disability nursing over thirty years has a personal meaning to me as I submit this study for examination in the week that I qualified as a learning disability nurse exactly thirty years ago. It has been a privilege to hear the stories of learning disability nurses in this study and it is a privilege to be part of the profession of nursing and the field of learning disability nursing.

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## Appendix 1: Search terms

Database	Boolean/phrase	Hits	Relevant papers	Publication date	Limiters
	Learning disability AND Nurses AND Nursing			1990-2010	English Academic Journals dissertations
CINAHL Plus with full text		273			
MEDLINE		184			
	Mental Handicap AND Nurses AND Nursing				
CINAHL Plus with full text		42			
MEDLINE		36			
	Intellectual disability or mental retardation or learning disabilities AND Nursing AND nurses				
CINAHL Plus with full text		449			4 dissertation not relevant
MEDLINE		365			
ASSIA	Learning disability AND Nursing AND Nurses	112	60		
	Mental Handicap AND Nursing AND Nurses	8	5		
	Intellectual disability or mental retardation or learning disabilities AND Nursing AND nurses	18	3		

BNI	Learning disability AND Nursing AND nurses	12 60  126  756 5,673	0 1  0 40 (refined search leading to 125 )	1960 -69 1970 -79  1980 -89 1990 -99 2000-2009	
	Mental handicap AND nursing AND nurses	16 20 55 121 570	0 0 2 6 8	1963-1969 1970-79 1980-89 1990-1999 2000-2009	
Proquest dissertation & Theses		402	4	1956-2009	

## Appendix 2: Online invitation



Hi

I am a learning disability nurse/lecturer undertaking a PhD looking at the experience of learning disability nursing in England over the past 30 years from the perspective of learning disability nurses. I will be collecting narrative accounts through interviews (both online and face to face). If you are interested in participating in the research you can email me at [ldresearch@btinternet.com](mailto:ldresearch@btinternet.com) for further information.

Thanks

Nicky Genders

### Appendix 3: Invitation letter



De Montfort University  
Faculty of Health & Life Sciences  
School of Nursing & Midwifery

26<sup>th</sup> June 2009

Dear

You are receiving this email invitation because you responded to a recent advertisement on a social networking site.

I am a lecturer in learning disability nursing and PhD student at De Montfort University. I would like to invite you to participate in my research project entitled **30 years of learning disability nursing in England: A narrative study**. I have attached the participant information sheet, please have a look at this before deciding whether you would like to be involved. If you would like to take part in the study please contact me by replying to this email address. If I do not receive a reply within 3 weeks of the email sent date then I will ensure your email details are removed from my PC and you will not be contacted again.

I look forward to hearing from you

Nicky Genders

## Appendix 4: Participant information sheet



### Participant information



Hello I am Nicky Genders and I would like to invite you to participate in the research described here. Please read all information carefully

### Study title: **30 years of learning disability nursing in England: A narrative study**

#### Invitation

You are being invited to participate in a research study but before you decide whether you would like to be involved it is important to understand what the study is about, why it is being undertaken and what your role as a participant would be. Carefully consider the information contained here and discuss it with other people if you wish too.

#### Purpose of the study

The study aims to investigate the lives and careers of learning disability nurses in England over the past 30 years. As you are aware policies around community care for people with learning disabilities has been shaping the way in which learning disability nurses work since the late 1970's. This study hopes to explore the ways in which this has impacted on the work and the professional identity of the learning disability nurse.

#### Who has been chosen

There are approximately 24, 000 learning disability nurses on the Nursing & Midwifery Council's Register. This study is particularly interested in nurses working with people with learning disabilities either in NHS or non NHS setting who went on the Register between 1979 and 2008. The study aims to recruit 10 -16 learning disability nurses across England.

### Taking part in the study

It is up to you whether you take part in this study, if you decide to you will be asked to keep this information safely and to sign a consent form to say you have agreed to take part. If you decide not to take part then you do not need to do anything and you will not be contacted again.

If you decide to take part and then change your mind at any point during the study you are free to withdraw without any consequence and any data collected will be securely disposed of and not used in the study.

If you are happy to take part in the study you will be asked to participate in an interview that will last up to 2 hours, scheduled at a time and in a place that suits you. This could be your workplace (with the agreement of you Manager), your own home or some other location such as a cafe. All we need is that it is relatively quiet to enable our voices to be recorded. The interview would be in two parts (taking place on the same day) in the first part of the interview the researcher will ask a very broad question about your career as a learning disability nurse and give you an opportunity to talk about this without interruption from the researcher. With your permission, the interview will be recorded using a digital voice recorder and the researcher will also take some notes as you speak. There would then be a break of 10-15 minutes and following this you would be asked more focussed questions based on the information you gave in the first part of the interview. After the interview the information will be transcribed and a copy of the transcription sent to you for checking. You will also be given the opportunity to comment on the transcription either by sending comments to the researcher or by taking part in an online interview.

### 3<sup>rd</sup> phase: online interview.

Approximately 3 weeks after your face to face interview you will receive an email asking you if you would like a copy of your transcript for comment and the opportunity to take part in an online interview. The online interviews will take place using an instant messenger system. The conversation will be one to one and both parties will be provided with the means of authenticating the other person's identity. Although extremely unlikely, be aware that it is possible that the conversation could be intercepted or monitored by a third party, and therefore it is vital to ensure that you do not reveal details that could compromise either you or your clients.

You do not have to participate in this 3<sup>rd</sup> phase interview and can add your comments or thoughts by email or telephone directly to me the researcher. If you do take part in the online interview this will take place at a mutually agreed time in a place where you can ensure a degree of privacy as you type your 'conversation'. It should last for no longer than 30 minutes and the 'transcript' of the conversation will be saved to a secure server.

### Analysis of your information.

During the analysis phase of the research your transcript may be viewed by others involved in analysis however this transcript will have all personal details removed and codes used to ensure you cannot be identified.

All information collected during this study will be stored securely either in the case of 'hard copies' in a securely locked filing cabinet or for electronic data on a secure server which is password protected. All transcripts of interviews and related information will be anonymised and identified only by codes.

### Advantages and disadvantages of taking part in this study

There may be no advantages or disadvantages to you taking part in this study however some evidence within the literature points to the benefits of nurses reflecting upon their professional practice. The study will contribute to a body of knowledge around learning disability nursing which in the current climate of change and doubt over the role of the learning disability nurse will assist others to understand the key role the nurse plays in the life of people with a learning disability. Your involvement in this study will help the researcher to understand the identity and career of the learning disability nurse. It is envisaged that this will also inform education and future policy and practice.

Taking part in the study is unlikely to have any disadvantages to you other than finding the time to take part in the interview. As a nurse, I am accountable to the NMC and am required to report any unsafe practice that may be described (NMC 2007)

#### The results of the study

The results of this study will be written up into the PhD thesis and may also be used in the future for conference presentations or journal articles. At no point will individuals be identified and confidentiality and anonymity will be maintained.

#### Who do I contact if there is a problem?

If you have any complaint about the way in which the study has been undertaken you can contact:

Ms Angela North-Rose (Head of School of Nursing & Midwifery)  
De Montfort University  
Charles Frears campus  
266 London Road  
Leicester  
0116 2013878

#### Funding of the study

This study is part of a PhD funded by DeMontfort University, Leicester.

#### Review of the study

The study has been reviewed by the De Montfort University Research Ethics Committee to ensure it meets appropriate standards for ethical research.

#### Contact details

The researcher contact details are:

Nicky Genders

DeMontfort University, Charles Frears Campus, 266 London Rd. Leicester

0116 2013911

[ngenders@dmu.ac.uk](mailto:ngenders@dmu.ac.uk)

Specific email address for research correspondence: [ldresearch@btinternet.com](mailto:ldresearch@btinternet.com)



## Appendix 5: consent form



Participant Identification Code for this study:

### CONSENT FORM FOR PARTICIPANTS

**Title of Project: 30 years of learning disability nursing in England: A narrative study**

**Name of Researcher: Nicky Genders**

Please initial the  
boxes below where  
you agree with the  
statement

1. I confirm that I have read and understand the information sheet dated 16/4/09 (version 4) for the above study.
2. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my employment or legal rights being affected or my employer being informed.
4. I understand that sections of data collected during the study, may be looked at by individuals from De Montfort University, or from regulatory authorities. I give permission for these individuals to have access to the data provided by me in the interview.
5. I understand that anonymous direct quotes from my interview may be used in published reports and/or conference presentations.
6. I agree to take part in the above study.

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

_____ Name of Person taking consent	_____ Date	_____ Signature
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When completed, 1 for participant; 1 for researcher file;

## Appendix 6: Ethics approval

## Appendix 7: Conference Presentations

10th annual interdisciplinary research conference Dublin Nov 09 **Understanding the Learning disability Nurse: a narrative approach**

Learning Disability Leadership Conference Derby UK Sept 10 **Poster presentation 30 Years of learning Disability Nursing: A narrative approach.**

Positive Choices conference Hertfordshire April 2011 **Understanding the learning disability nurse: A biographical narrative approach.**

International Association for the Scientific Study of Developmental Disability World Congress. July 2012 Canada **Shaping policy and provision for people with intellectual disabilities in England: change from within**

Decide, Commit, Proceed Leadership Workshop (July 2013) **Identity and Leadership.**

Open University. Social History of Learning Disability Conference. Exploring Positive Practice in Learning Disability: past and Present (July 2014) **30 Years of Learning Disability Nursing in England.**

## Appendix 8: Published article

Genders, N & Brown B. (2014). Who chooses to be a nurse and why? A narrative study  
Learning Disability Practice. Jan 30, 14

(needs scanning in )